Building Resilience in mothers caring for neurodivergent children: A Multi-Framework Approach using Personal Resources and Self-Regulation.

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ABSTRACT

In the UK, approximately one in seven people may be neurodivergent. Parent caregivers of neurodivergent children frequently experience elevated stress, anxiety, affiliate stigma, isolation, and reduced social support, which negatively impact their homelife, careers and workforce participation. Employing conservation of resources (COR) theory and regulatory mode, this PhD study sought practical approaches to improve mothers' resilience and coping mechanisms. Two research gaps were identified: the associations between COR and regulatory mode, and the potential application of these theories in supporting mothers who care for neurodivergent children. To address these issues, crosssectional, semi-structured in-depth qualitative interviews were conducted with 19 mothers. The results identified links between COR and regulatory mode. Data and results identified links between COR and regulatory mode. Key resources and four novel resource passageways, including a conceptual opening passageway, were determined. The study contradicts previous findings on long-term time investments and validates the relevance of the crossover model and broaden-and-build mechanism for this cohort. Practical strategies for supporting mothers caring for neurodivergent children are identified. Findings both extend and challenge the COR and regulatory mode frameworks. Proposals to support parents of neurodivergent children expand the use of the two frameworks, and findings add to COR and regulatory mode literature by understanding how these parents handle life stressors. The outcomes potentially aid other caregivers and employers by offering targeted guidance and interventions to bolster resilience and coping strategies.

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Abbreviation	ons
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
BFP	Brighter Futures Project
Bn	Billion
CAD	Cumulative Advantage and Disadvantage
CBGT	Cognitive Behavioural Group
COR	Conservation of resources (theory)
EE	Emotional Exhaustion
HMG	His Majesty's Government
IT	Information Technology
MS	Microsoft
РТ	parent Training
RAG	Red Amber Green
RQ	Research Question
SEN	Special Educational Needs
SEND	Special Educational Needs and Disability
QoL	Quality of Life

UN SDG United Nations Sustainability Goals

UREC University Research and Ethics Committee

1 Introduction

This chapter is an introduction to the study that is presented in this thesis. It provides the rationale for the thesis and addresses the key aspects of the phenomena studied. It will underline the background and context of the study, the focus of which is the development of practical interventions using conservation of resources (COR) theory and regulatory mode, to strengthen the resilience and coping mechanisms of parents caring for neurodivergent children. Review of these two psychological frameworks and determining whether a meaningful relationship between them can be established were key to this study and the development of the proposed interventions. The findings from this study are summarised and compared with prior research. Where relevant, contradictory results are explored. Gaps in the existing literature, specifically relating to links or associations between COR and regulatory mode, and the applicability of the two psychological constructs to mothers caring for neurodiverse children, are noted by reviewing available research. Opportunities for further research are considered. I draw on and review my research method and methodology and discuss my background in the research area and how this impacted my approach. Finally, I provide a summary of the content of each of the research chapters that follow.

The aim of this study was to develop initiatives to support mothers caring for neurodivergent children using COR, and assessment and locomotion within regulatory mode. No papers could be found in COR theory combining resource states and regulatory mode orientations of assessment or locomotion. Research in regulatory mode considering explicit links between personal resources and an individual's resource situation is negligible. This represents a gap in literature. Although regulatory mode studies frequently use the term resources, it is used in its broadest sense, as a supply or reserve of personal capacities, rather than referring to the complexities of resources and the principles and corollaries developed within the COR theory. This study therefore sought to gain greater understanding of how COR and regulatory mode theories may be associated. Additionally, I was unable to find studies in the fields of COR or regulatory mode that examined how the two domains relate to mothers caring for neurodivergent children. Although previous studies have pointed to the potential application of each theory to such mothers, it is

evident that there is a gap in the literature concerning whether and how the two theories can be used to support mothers caring for neurodivergent children.

In summary, two research gaps are identified: associations between COR and regulatory mode, and how the two theories might be used to support mothers caring for neurodivergent children. Developing support initiatives for mothers caring for neurodivergent children using COR and regulatory mode needed an understanding of the extent to which the two constructs were associated and worked together. If this was not clear from prior literature, I believed that the initial objectives of this study needed to address that gap.

The literature gaps

COR research has not effectively explored both regulatory mode and personal resources together. Tesi (2021) studied the regulatory mode and job demands-resources (JD-R) model, emphasising job and personal resources in goal achievement. The study found that locomotion was linked to higher work engagement due to personal resources but focused on regulatory mode theory and the JD-R model, not COR. Tesi did not expand on this theme but later considered resources through job demands and work constraints within the JD-R model (Tesi et al., 2024). Halbesleben et al. (2014) proposed self-regulation might influence resource trajectory cycles, suggesting new resources may enhance goal achievement more than existing ones. However, they did not specify resources. Halbesleben later co-authored work on regulatory focus and resource cycles, without advancing the 2014 study (Paustian-Underdahl et al., 2023). Other COR research broadly refers to self-regulation as an individual control. Kakavand et al. (2019) found corrupt behaviour as a response to perceived threats to work resources tied to self-regulation for resource preservation. Diestel (2022) studied self-control demands for coping with job demands that required self-regulation. Gerpott et al. (2022) suggested that self-regulation depletes regulatory resources, leading to ego depletion.

Regulatory mode links with conservation of resources

Numerous regulatory mode studies have referred to time as a resource, and some other resources have been referenced. Research suggests that resource scarcity, in a generic sense, is important (Shah et al., 2012; 2015). Kruglanski et al. (2000) refer to psychological

resources. Kruglanski et al. (2016) viewed time generically as a resource essential to attain valuable and measurable things. Lucidi et al. (2016) examined potential stress development in locomotors if they continuously mobilised personal resources for goal pursuit, noting their protective value. Lee-Yoon and Whillans (2019) noted that time is a finite, precious, and scarce resource. Amato et al. (2019) provide a significant link between regulatory mode and COR theory, referencing time as a resource. They highlighted the value locomotors place on time to progress and achieve goals, establishing it as a resource for goal achievement. There is no reference to time within the COR context, as the focus is specific to goal achievement, emphasising its temporality value. Amato et al. (2019) suggests potential for further associations, recommending future research considers resources other than time, such as money. However, after reviewing subsequent publications, it does not appear that the proposal was taken forward by the authors of the 2019 paper.

Despite limited research on regulatory mode orientation and COR theory, the links between the two are apparent. Prior COR studies overlooked a person's regulatory mode orientation and vice versa. I consider these important omissions. The literature review for this study suggests that an individual's resource situation may significantly influence their approach to goal movement and achievement (Jansen et al., 2022) and affect resource protection and generation. It is likely that the failure to protect, create, or sustain resources may be related to an individual's assessor or locomotor orientation. Equally, it is likely that not considering locomotion and assessment orientation in COR research may fail to consider pertinent factors influenced by the psychological frameworks.

Background and Context

Neurodivergent conditions include but are not limited to, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy (CP), Tourette syndrome, and some learning disabilities, such as dyslexia and dyscalculia. To clarify terminology, non-neurodivergent individuals are typically considered neurotypical. Neurodivergent describes individuals with less typical cognitive variation than those with typical developmental, intellectual, and cognitive functioning. An individual is neurodivergent; a group of neurodivergent individuals are neurodiverse, with neurodivergences. Neurodivergence is a chronic condition, and neurodivergent children are considered to have special needs.

Many parents face difficulties with the care of their children from time-to-time, but parents of neurodivergent children routinely experience substantially greater daily struggles to meet the needs of their children while maintaining their own well-being, compared to parents of neurotypical children. Around the period when I interviewed the mothers in my sample, news items reported parents experiencing mental health breakdowns, giving up work, and borrowing money to fund private medical assessments so that their children's needs could be recognised, because local assessment provisions fell short of demands (BBC, SEND kids failed, 2023). Local news reported that a 19-year-old neurodivergent teenager had not attended school for eight years, since age 11 (BBC, pupils miss school, 2023). The number of people diagnosed with neurodiversity is increasing, and practical and realistic solutions are needed to help their parents.

This study focusses on the psychological frameworks of COR and regulatory mode. It considers the concepts of resource caravans and resource passageways within the conservation of resources theory, as well as the self-regulatory orientations of assessment and locomotion within regulatory mode. The importance of time, and social support as vital resources in both the psychological frameworks, and their impacts on psychological and physical functioning, are highlighted.

Key resources for the mothers are identified, and clustered to form distinct resource combinations for the mothers. Identifying these clusters of resources helped to determine how the mother-carers could be grouped, and in doing so, may support the development of bespoke support frameworks linked to the strength or weakness of the individuals resource situation. Recognising key resources and how they cluster for individuals supported the development of the proposed practical approaches to improve resilience and coping mechanisms for mothers caring for neurodivergent children, which was the primary purpose of this research.

Neurodiversity

Neurodivergent conditions typically emerge in early childhood, although poor understanding of children's behaviours, and delayed assessment, can lead to diagnosis in late childhood, teenage years, and, increasingly, during adulthood. Whenever the diagnosis is made, neurodivergent children require additional support and time, compared to their neurotypical peers. This routinely leads to caregiver (i.e., the parent caring for the child)

anxiety and strain through the parents' limited knowledge of the child's condition, conflict through advocacy, pressures on parent's time, and work-life balance. In addition, strained social connections can lead to reduced support and affiliate stigma. These can have long-term effects on parental well-being, which can negatively impact career paths, affecting parents, and families. It can also negatively affect employers, through the loss of valuable employees.

Neurodiversity is a common global phenomenon. Approximately 700,000 individuals affected in the United Kingdom (Autistic Society, 2024). More broadly, 15%, or one in seven people in the United Kingdom (UK) are considered neurodivergent (ADHD Aware, 2024; Boland and Burgess, 2023; Somerset and West Taunton, 2020). The number of individuals diagnosed with autism and ADHD in the UK is increasing (Psychology Today, 2023).

The special needs system is becoming financially unsustainable, and although the UK government has increased funding for such needs by over 50% since 2019, there have been few improvements in outcomes or experiences (HMG SEND Review, 2022; HMG SEND Plan, 2023), with a five-fold rise in people waiting to see an autism specialist (BBC News, 2024). More than 183,000 people in England are now waiting for an autism assessment: an increase of 39% in the last year (Autistic Society, 2024). With such challenges, there is a need to find ways to help parents caring for neurodivergent children, to support them during their journey, and reduce risks to their own wellbeing, that of their children, and those around them.

Neurodevelopmental conditions vary and require different approaches and interventions. ASD encompasses behavioural issues, language difficulties, social deficits, hyperactivity, and aggression. ADHD symptoms include impulsivity, hyperactivity, and inattention, which affect communication and social interaction. As a result, neurodivergent children routinely require additional support, and these obstacles can impact both the caregiver's well-being and their families.

Impacts of neurodivergent childcare on parents

Children with neurodevelopmental conditions commonly present with challenging behaviours (Estes, 2009), leading to parental strain, anxiety, stress, and depression (Jellett

et al., 2015; Lecavalier et al., 2006). Stressors arise when situational demands exceed available resources (Webster-Stratton, 1990). Higher parental stress can also exacerbate neurodevelopmental behaviours (Lecavlier et al., 2006), with effects on parents and children (Benson and Karlof, 2009; Hastings, 2003). These challenges can upset parent-child relationships and may lead to maladaptive parenting (Van Steijn et al., 2014).

Stress from concerns about a child's future, family finances, and relationships can lead to exhaustion, depression, and anxiety (Brown et al., 2008; Coffey, 2006). The outcomes of these stressors affect families (Smith and Kaye, 2012), social networks (Gustafsson et al., 2002), and the careers of parents (Murray et al. 2007). Parents of neurodivergent children may experience a lower quality of life than those caring for neurotypical children (MacKenzie and Eack, 2022; Vaz, 2022). Emotional, psychological, and family challenges are common, and parents of neurodivergent children face poorer health, career, and well-being outcomes than parents of neurotypical children, and children with disabilities (Padden and James, 2017; MacKenzie and Eack, 2022;).

Neurodivergent symptoms in children commonly lead to caregiver stress (Cervin et al., 2020; Gissandaner et al., 2023; Lecavalier et al., 2006). However, Falk et al. (2014) and Minnes et al. (2015) suggest that other factors such as financial situation, reduced social support, and psychological challenges may also influence the level of stress experienced by caregivers of children with neurodivergent symptoms. Challenges related to ASD result from social stigma, financial concerns, and navigating support systems (Bonis and Swain, 2016; Pilapil et al., 2017; Serrata, 2012). Parents of neurodivergent children also face anxiety, anger, depression, and stress (Hayes and Watson, 2013; Zabotsky et al., 2013). Parental coping strategies involve emotion-focused and problem-solving approaches (Reddy et al., 2019); however, parents may also adopt harmful avoidance behaviours (Lai and Oei, 2014). Supporting neurodivergent children generally leads to time-pressures that affect the wellbeing of their parents (Schilbach et al., 2023; Vasilopoulou and Nisbet, 2016).

Social support

The additional responsibilities of parents caring for children with chronic conditions can affect a family's social interactions. Families of children with complex needs may receive little help or support from friends or family, and this has been linked to caregiver fatigue

(Caicedo, 2014; Kuo et al., 2011). Strain, and time pressures on parents can reduce social connections, with associated affiliate stigma commonly affecting parents' well-being and reducing the benefits they can gain from social support networks (Lovell and Wetherell, 2019; Mikulincer and Shaver (2022)). Parents providing long-term care for their children can also be emotionally unable to disengage from their caring responsibilities, with the resulting stressors reducing their effective engagement (Schaufelli et al., 2002) and alienating them from friends and others (Maslach and Leiter, 2008). Accepting support from loved ones is an important adaptive coping strategy that provides relief from stressors (Fairfax et al., 2019) helping parents address pressures and challenges.

Work, Employment, and finance

Working parents of neurodivergent children face increasing conflict between work and family, exposing the complexities of balancing caregiving responsibilities with career ambitions (Balachandran and Bhuvaneswari, 2024). Parents can struggle to balance caregiving responsibilities and participation in meaningful activities such as work, if they are to maintain life quality (Davy et al., 2023). Recent studies highlight the value placed on work-family equilibrium and work culture by these parents (Stevens et al., 2024). Parents caring for children with long-term needs can struggle to maintain their careers, workhours, and family incomes. Brown et al. (2008) noted a strong link between a child's health and family income related to home-work balance, and Kish et al. (2018) found that parents who continue working can still face financial challenges that affect their quality of life, especially in the case of single parents (Thomas and Sawhill, 2005). Parents of children with special healthcare needs frequently sacrifice aspects of their employment (Easterly et al., 2022), with some discontinuing work (Kuo et al., 2011). However, some studies have found no significant association between challenges to finances, working hours and caring for sick children in low-income families (Loprest and Davidoff, 2004; Montgomery et al., 2002). Others have found that parental stress is tied to parents' ambitions for their sick child rather than hours worked (Rockwool Foundation Research Unit, 2010). Whilst reduced work commitments by mothers can lead to them having more time with their children, time spent in work can lead to home-work conflicts that can affect health and well-being (George, 2011; Schaufelli and Tarris, 2014; Van Campen and Cardol, 2009).

Health support to parent carers

Parents of children with chronic conditions experience greater depression and anxiety (Asbury et al., 2021) than parents of healthy children (Cohn et al., 2020). This can lead to parents seeking help for themselves, although the findings on parental access to healthcare are contradictory. Shah et al. (2012) discovered that mothers of chronically ill children accessed mental health services 22% more than mothers of unaffected children, with the mothers having a 59% greater use of psychotherapy. This was most common among lower-income mothers with children aged 7–13 years. Cousin and Hazen (2014) suggest that parental stress is linked to managing the child's care and psychological adjustment, rather than the child's diagnosis.

Psychological interventions for parents of chronically ill children have yielded mixed success. Although problem-solving therapies have been found to be beneficial, a Cochrane review found little support for interventions targeting caregivers' mental health (Eccleston et al., 2015). Caregivers of children with diabetes (another long-term health condition with uncertain outcomes) were found to benefit from practical coping training (Grey et al., 2011), and help with managing uncertainties (Hoff et al., 2005). Eccleston et al. (2015) found that cognitive behavioural group therapy (CBGT) could help parents cope, create resilience, and deal with stressors, and relatively short interventions led to positive psychological effects in mothers of children with autism (Izadi-Mazidi et al., 2015). Iadarola et al., (2018) found that parent training (PT) can be effective in reducing disruptive child behaviour, increasing parental competence, and decreasing stress and strain.

Recent interventions to develop support for parents caring for children with neurodiversity, and more generally, special needs, have developed programmes that focus on family centred interventions (McConkey et al., 2023). Interventions are often community and home based (Mullan at al., 2021; Zuurmond, 2019), using systems-based approaches (Guralnick, 2023). The focus is on early intervention to build parental confidence and ability through better information, knowledge, community and social connections, and child development initiatives (Amsbary and Able, 2023). These programs develop mental and emotional well-being and hope through self-development, empowerment, and self-confidence (McConkey et al., 2023). In addition, increasing

attention is being paid to mindfulness, and compassion-based interventions to aid parental resilience through adaptive stress appraisal and coping (Cousineau et al., 2019; Kemp, 2024). COR has been proposed as a framework to explain how mindfulness may support motivation and work in organisational settings (Kroon et al., 2015), which may also be relevant to mothers caring for neurodivergent children.

Conservation of resources theory

Conservation of resources (COR) theory is a stress, resilience, and motivation theory that reinforces the importance of wider social relationships and interactions (Hobfoll, 2001; Westman et al., 2004). It outlines a process of objective interpretation and prediction of the positive and negative impacts of stressors on individuals, which determines their consequent behaviour and resilience (Chen et al., 2015; Ford, 2009; Hobfoll, 2001). The theory proposes that an active relationship operates between an individual's resources, the contexts in which they exist or are used, and the individual's environment (Neveu eta l., 2023). The concept of resource caravans was developed by Hobfoll (2011a), who argued that resources do not exist or act in isolation but are grouped and travel in caravans. Caravans are created in ecological circumstances which either limit and block or foster and nurture an individual's resource caravans through circumstances largely outside their subjective control (Hobfoll, 2012).

COR theory recognises that circumstances that threaten or deplete personal resources are objectively stressful, and that psychological stress can occur when coping options are reduced (Hobfoll, 2001). COR studies have argued that humans are naturally motivated to protect and acquire resources (Westman et al., 2004), and that the loss of valued resources is disproportionately more salient than their gain (Hobfoll et al., 2018). Resources are developed and lost throughout people's lives, through cumulative advantage and disadvantage (Bask and Bask, 2015; Ferraro and Morton, 2018) and COR theory refers to the ebb and flow of these developments as resource passageways (Chen et al., 2015; Hobfoll et al., 2018). Individuals use their accumulated resources to respond to stressors and build and enhance their reservoirs of resources to sustain them for future needs (Holmgreen et al., 2017). People generally possess sufficient resources to cope with stressors by drawing on their resource caravans (Hobfoll and Hou, 2025) if stressors increase or persist (Hart and Cooper, 2001). However, prolonged or significant resource

use may deplete an individual's resources so significantly that they begin to experience stress, exhaustion, and potential burnout (De Cuyper, 2012). COR studies have argued that these stressful events present predictable objective elements of threat and loss, with common appraisals held jointly by people who share a common biology and culture through which they assess and approach their lives (Chen et al., 2015).

Individuals are less likely to be adversely affected by stressors, negative events, or circumstances if they have a well-established resource caravan. People's stress levels increase in circumstances that threaten, or lose resources, such as may occur where a parent needs to juggle their family and work roles (Greenhaus and Parasuraman, 1999). This resource loss may lead to perceived psychological conflict, resulting in increased stress, which could occur when a working mother caring for neurodivergent children is conflicted by needing to balance work to earn more income against spending more time with her children. An alternative more positive view of family, and working life, was put forward by Nicklin et al. (2019), who suggested that multiple roles may provide individuals with the scope to increase their personal resources, resulting in work-family enrichment (Greenhaus and Powell, 2006). This may be linked to the crossover model (Westman, 2001; Chen et al., 2015; Li et al., 2021; Sha and Huang, 2024) and the broaden-and-build mechanism (Fredrickson, 1998, 2000). This positive psychology assumes that the accumulation of resources from one role may be advantageous in another, allowing the working parent to draw resources such as finance, mastery, self-esteem, and positive effect, from the work (or another) role, to benefit their family situation (Nicklin et al., 2019).

COR studies have acknowledged that there is an individualistic component to personal resource allocation, whilst noting the more objective COR construct (Grawitch et al., 2010). A more substantive body of COR research argues that individuals take an objective approach to dealing with stressors and stressful situations (Hobfoll, 2001) to protect and acquire resources (Westman et al., 2004), and support future needs (Holmgreen et al., 2017). COR theory's focus on objectivity supports its assumption that individuals strive to create and maintain a resource position, and this could be used to create a stable base, a position favoured by individuals with assessor orientations. Alternatively, it could also support the concept of striving to create a platform for movement from a current to a future state, which would be favoured by locomotors (Jansen et al., 2021). These

conceptualisations may provide a basic relationship between COR theory and regulatory mode, from which subsequent associations can be explored.

Regulatory mode

Regulatory mode is a key construct within self-regulation ((Jansen et al., 2022; Mischel, 1973; Tiemouri et al., 2022), which articulates the capacity to regulate cognition and behaviours, providing us with a coping tool to reduce negative effects (Schlaegel et al., 2022). The two personal orientations of goal pursuit within Regulatory mode are assessment and locomotion (Kruglanski et al., 2000). Goal pursuit considers an individual's desire to move from their current state to a desired alternative future state. Assessment encompasses the evaluation and deliberation of goals and the potential means of effectively achieving change (Kruglanski et al., 2000). Locomotion focuses on the initiation and sustainment of actions and movements from a person's current state to a new desired state (Jansen et al., 2022).

Like COR theory, which emphasises resource protection to maintain personal well-being and provide for future needs (Holmgreen et al., 2017), regulatory mode theory highlights an individual's drive to control their present and future well-being (Kakavand et al., 2019) through change. Both assessors and locomotors may have higher or lower proclivities within their orientations, suggesting that they may be a high or low assessor or locomotor. An individual's need to change their present situation is amplified in people with high locomotion orientations who seek rapid, decisive progress towards goals. Conversely, high assessors will focus on goal options and may prioritise savouring their current experiences, with little desire for movement (Orehek et al., 2017). The extent to which people are sensitive to, or focus on, assessment or locomotion can vary, with individuals naturally, or from time to time, having a bias towards one or the other (Orehek et al., 2017). An individual's self-motivational orientation may also influence the effort they commit to maintaining or developing personal resources.

Loss or gain of personal resources can significantly influence psychological outcomes, and the impacts are more complex and comprehensive compared to simple coping behaviours (Freedy et al., 1992). Resource loss and gain can affect how people perceive their ability to progress or regain their situation, as well as coping mechanisms they can develop and deploy (Benight et al., 1999). However, personality (Amato et al., 2019; Kruglanski et al.,

2016), and context (ten Brummelhuis and Bakker, 2012; Fan and Potočnik, 2021) can also be important factors, and may make the regulatory modes of assessment and locomotion (Kruglanski et al., 2000) key contributors for how parents caring for neurodivergent children manage their resources and, more widely, their daily lives.

Time

Time is considered a vital resource in COR and regulatory mode (Amato et al., 2019; Lee-Yoon and Whillans, 2019; Pavlova, 2021). Goal movements require resource investment, particularly time. High locomotors use time to move forward, but high assessors are likely to be preoccupied with how to best use time (Higgins et al., 2003; Kruglanski et al., 2000; Kruglanski et al., 2013). Higher locomotors do not waste time when committing to change, and experience greater upset or even stress from poor time use (Scholer and Higgins, 2012); however, the desire to move forward is rarely crucial for high assessors. Assessment and locomotion modes do not function in isolation, and each constrains and supports the other in goal pursuit with one informing and guiding, and the other ensuring action (Higgins, 2012). This differentiates the importance of time in the two regulatory mode orientations, although it is nevertheless vital for both locomotors and assessors (Amato et al., 2019).

Time is also an essential resource in COR theory (Fan et al., 2021; Mühlenmeier et al., 2022; Pfeffer and Carney, 2018; Schilbach et al., 2023). The resource caravan concept (Hobfoll, 2012; Hobfoll et al., 2018) posits that resources work in concert. This may link to the regulatory mode construct, where time is essential for goal movement (Xanthopoulou et al., 2009). There are other examples of resources working together in both the psychological frameworks. The resources of self-esteem, self-efficacy and optimism are considered to function jointly in core theory, and are linked, along with social support, to locomotion in regulatory mode for effective task and work engagement as well as psychological vitality and positivity (Pierro et al., 2008; 13a, b). By supporting goal achievement, these resources reduce the experience of low self-esteem, depression, psychological stress, and burnout (DeCarlo et al., 2014).

Time is therefore a key resource in COR theory and is a vital enabler in regulatory mode (Pfeffer and Carney, 2018; Lee-Yoon, and Whillans, 2019). The link between time, behaviours and both positive and negative cognitive effects are well reported in regulatory

mode research (De Voe and Pfeffer, 2007b). The association of time with money, employment, and social and prosocial behaviours in regulatory mode (Whillans and Dunn, 2015; 2019) resonates with COR theory, where resource caravans and passageways are profoundly linked to employment, social behaviours, and connections (Pavlova, 2021; Clissold et al., 2021). There are also important links between the psychological frameworks of COR and regulatory mode, and people's emotions and resilience (Lock and Dunn, 2022; Okada and Hoch, 2004).

Social connections

Social exchange is important in both the psychological frameworks, as social connection supports social belonging, acceptance, and support (Epley and Schroder, 2014; Baumeister and Leary (2017; Leary, 2005). However, socialising occurs at the cost of other activities such as work or childcare (Whillans and Dunn, 2019). Restricting social interactions can lead to work-related social disconnection and personal sadness (Williams and Dunn, 2019). Personal affect resulting from an individual's regulatory mode orientation are related to their social situation (Carvalho et al., 2016), and the quantity and quality of an individual's social connections have been shown to have a profound impact on their psychological and physical functioning (Uchino et al., 1996) and the risks of seclusion. COR theory also recognises the importance of social support resources for mental health (Hobfoll et al., 2012).

Key associations: COR and regulatory mode

A person's regulatory mode and resource situation can be situational, enduring, or a nuanced combination of the two (Orehek et al., 2017; Westman et al., 2004). However, a high locomotors desire and ability to move forward, supported by their time management abilities and techniques, may be tied to their resource caravan and caravan passageways (Hobfoll, 2018) through their wider ecology. A high locomotor's need for movement may be related to their desire to continually protect their resources, but also their capacity to facilitate change through a strong resource situation coupled with a desire to continually augment their resource reservoir, which may establish a perhaps obvious, but convincing link between the two frameworks.

The associations between the frameworks may connect other facets, such as locomotion and a strong resource situation through a locomotor's adoption of time management strategies, such as task focus, reduced delays, and low procrastination (Pierro et al., 2018). It may also provide insights into the factors limiting the use of an individual's resources to augment or protect their resource situation. These could include an assessor's proclivity towards rumination (Lu et al., 2021), anxiety, depression, low self-esteem (Litwiller et al., 2017), and possibly a more challenged resource situation.

There are apparent links between the COR principles and corollaries (Hobfoll et al., 2018), and regulatory mode. COR Principal No. 4, the desperation principle which highlights irrational behaviours, might be associated with a high locomotors desire for movement and change regardless of the consequences. Conversely, it may be associated with a high assessor's proclivity to ruminate, or maintain the status quo, even though they may need to address an issue urgently. COR Corollary No. 2, which articulates the spiralling speed and intensity of resource gain and loss, could be associated with high locomotors optimisation of the use of their time because they consider it a scarce and finite resource (Jansen et al., 2022), as poor use can lead to significant negative effects. This negative effect is likely to be more severe and significant for a locomotor than for an assessor.

Linking the COR corollaries to the regulatory mode invites additional enquiry through future research If an individual's regulatory mode can be associated with their resource situation, the resulting behaviours and cognitive consequences of either locomotion or assessment may identify a new personal and dyadic dynamic to explore within COR research, and new avenues for research within regulatory mode. Linking high locomotion with more stable, stronger resource situations may add to our understanding of COR principles and corollaries (Hobfoll, 2018) and allow nuances to empirical research results through a better understanding of participants' self-regulatory differences. It may also add clarity to why the infusion of resources into those with fewer resources (Principal No.3, the gain principle) can produce a greater effect in some people than others, and with a more powerful impact, than in situations of resource loss.

Behavioural and cognitive effects associated with the two regulatory modes (Amato et al., 2019) may be linked to an individual's wider COR situation. Examples include reduced procrastination, impatience, and greater frustration due to poor time use (De Voe and

House, 2012), multitasking (Pierro et al., 2013), and less care with activities linked to decreased effort towards accuracy (Payne et al., 1996; Mauro et al., 2009). These behavioural consequences could affect an individual's resource conservation and generation, resource caravan, and wider resource caravan passageways. People's attitudes towards the value of time and how they use it can impact their subjective well-being and happiness (Whillans et al., 2016, 2017; Whillans and Dunn, 2019), which may consequently affect their resource reservoirs and resource caravan passageways.

Finally, linking COR and regulatory modes could expand our understanding of resource caravans, particularly resource caravan pathways, by refining our understanding of and possibly clarifying how some people's ecological conditions may support, foster, enrich, and protect an individual and why others may detract, undermine, obstruct, or impoverish their resource reservoirs. Despite the objective approach to COR theory, and in some respects, to regulatory mode, any practical support programs for mothers providing care for neurodivergent children must not only support and enable access to appropriate resources to prevent, limit, or stop resource loss spirals, but also generate and regenerate resource reservoirs.

Research aim, objectives, and questions

This research focusses on three distinct areas that coalesce to develop practical approaches to enhance parental resilience, coping mechanisms, and wellbeing for mothers caring for neurodivergent children. This research established one aim, with five objectives, and five research questions.

Research aim

The aim of this research was:

Using the theoretical and conceptual models of the conservation of resources theory, and assessment and locomotion, within regulatory mode, develop practical interventions to support mothers caring for neurodivergent children.

To address the aim, five objectives, with corresponding research questions were established (see Figure 1-1).

Objective	Research Question
1. To understand whether assessment and locomotion orientations may be associated with conservation of resources in mothers caring for children with neurodiversity's.	1. How do locomotion and assessment orientations relate to conservation of resources situations in mothers caring for neurodivergent children?
2. To explore personal resources employed by participants to help identify the basis for support interventions for mothers caring for children with neurodiversity's.	2. Using the combined lens of assessment and locomotion, and conservation of resources, can key resources, and common groupings or caravans of these resources be identified for mothers caring for neurodivergent children?
3. To examine how factors relevant to current resource situations and regulatory-mode orientations are shaped by, and relate to the life course experiences, of parents caring for neurodivergent children.	3. How do positive and negative resource passageways for mothers caring for neurodivergent children relate to current positive and negative resource caravans, and can links to the individual's regulatory mode be identified?
4. To investigate the impact of time, and social support, on parents caring for neurodivergent children.	4. What are the roles of time and social support for mothers caring for neurodivergent children?
5. To determine strategies to support parents caring for neurodivergent children, using the two psychological frameworks studied.	5. What practical interventions and approaches can be identified for mothers caring for children with neurodivergent conditions to support their resilience and enhance their coping capacity?

Figure 1-1: Research objectives and questions

Research background, development, and Methodology

The idea for this study was developed from a general interest in the extent to which the empirical data developed in quantitative conservation of resources (COR) studies adequately understood the depth of what participants were considering, their experiences, and their feelings when they responded to questionnaires. Empirical results lead researchers to interpret the reasons behind the results to understand individuals' motivations behind their findings. This study proposal was subsequently nuanced by asking whether what appeared to be a previously unlinked but possibly associated construct

of assessment and locomotion within regulatory mode may be influenced by an individual's resource situation, and conversely, whether an individual's COR situation may be influenced by their regulatory mode. Using these two theoretical models, this study initially sought to develop proposals to support parents providing long-term care for sick children.

The adopted design focus therefore initially aimed to develop an understanding of the day-to-day experiences of parents providing long-term care for chronically sick children. However, the non-probability purposive, and snowball sampling methods, recruited a sample who apart from one participant, were mothers caring for neurodivergent children. These mothers became the central phenomenon of the study and were people about whom the researcher had only limited preconceived assumptions regarding the practical and experiential challenges encountered in their daily lives.

This study adopts the research philosophy of phenomenological interpretivism, which is closely related to the interpretation and discovery of knowledge (Ferdiansyah et al., 2022). Interpretivism stresses the subjective nature of knowledge along with the value of understanding the interpretations and meanings developed by individuals within their own unique contexts (Miettinen, 2017). The phenomenological approach used attempted to understand what parents providing care for neurodivergent children were experiencing, through the reality of their subjective and inductively derived lived experiences (Merriam and Tisdell, 2015).

My subjectivism ontology contends that reality is created through our experiences and perceptions, where knowledge is dependent on the interpretations and experiences that we have as individuals, and on what we understand, derived from reflection rather than just lived experiences (Ormston et al., 2014; Voss et al., 2020). My interpretivist epistemological perspective emphasises the importance of understanding our interpretations and the meanings created within the unique contexts in which we experience them (Voss et al., 2020). This perspective highlights the importance of subjective experiences and the context in which they occur in shaping knowledge and understanding (Goldkuhl, 2012).

Supporting the reliability of this study, the qualitative research methodology adopted is routinely deployed in fields such as social sciences and health, where researchers are considered instruments in qualitative studies and the lens is focused on studying and interpreting experiences, attitudes, behaviour, and beliefs (Mays and Pope, 1995). Additionally, I provided transparency, detail, and openness about my data collection, and data analysis, which I saw as important components in minimising bias, and demonstrating validity and reliability of the results. A reflexive diary also contributed to the validity and reliability of this study.

Research method

An inductive research approach utilising qualitative data provided fresh perspectives to open new avenues for theoretical exploration (Bansal et al., 2018). In support of the validity of this study, this research was value-laden to both the researcher and the participants, who were biased in their life courses, experiences, culture, and knowledge (Al-Ababneh, 2020).

My research design used semi-structured in-depth qualitative online interviews with 19 mothers caring for neurodivergent children, recruited through purposive and snowball sampling. This design enhanced the representativeness of the study to mothers caring for neurodiverse children. The small, focussed sample, and inductive approach are likely to limit the generalisability of the results from this study. Notwithstanding this the results may also be reflective of parents who care for children with similar long-term, distressing and challenging conditions, which place similar emotional stressors and time pressures on their parents. Data analysis was performed using NVivo and Excel, following the process established by Braun and Clarke (2006), including coding and theme development. The use of an acknowledged research process augments the validity and reliability of this study.

Research journey

Starting in February 2022, my research reviewed prior literature on Conservation of Resources (COR) theory, later incorporating the psychological frameworks of COR and regulatory mode to support parents of chronically ill children. Although I initially considered a mixed-method approach, I used a qualitative methodology with a phenomenological interpretivist approach to deeply understand the parents I intended to interview.

While I acknowledge the significance of the positivist approach and the validity of quantitative research findings (Alessandrini, 2012), I emphasise the importance of reinterpreting participants' experiences and establishing meaning through new and enhanced interpretations (Crotty, 1996). This approach has ensured that the study focused on developing meaning within the phenomena as revealed through the participants' words and descriptions (Rasid et al., 2021).

By November 2022, the research project's concept was finalised, prompting a shift to participant recruitment and interview guide development. Despite recruitment challenges, 20 mothers volunteered to be interviewed, and following pilot interviews in early 2023, participant were interviewed between March and July 2023. The early research journey is summarised in Figure 1-2.

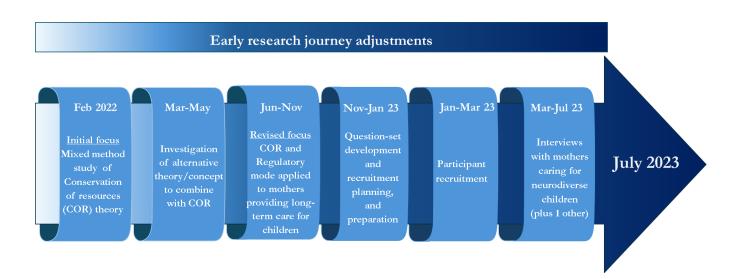


Figure 1-2: Early research adjustments overview

Despite efforts to recruit parents caring for chronically ill children as proposed, the initial participants were all mothers, with 19 out of 20 caring for neurodiverse children. Figure 1-3 outlines this early research journey. The recruited sample shifted the study's focus from parents of chronically ill children to mothers of neurodiverse children. Data from the twentieth interview with a mother of children with diabetes were excluded from the analysis, supporting the study's generalisability and representativeness by maintaining a

clearly defined participant group.

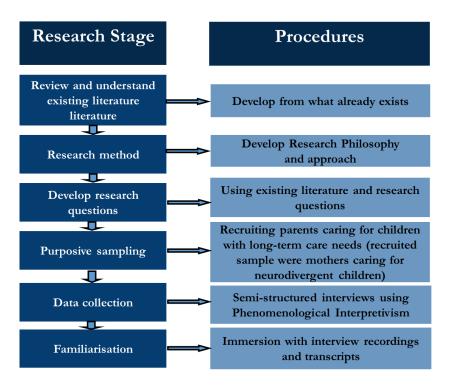


Figure 1-3: Outline of this study's early research journey

My approach as the researcher

As a researcher, I lacked direct experience with situations like those of the study participants. Consequently, I could observe and interpret but not fully comprehend or validate the emotional and physical impacts of providing care for neurodivergent children. I approached the interviews with an open mind, aware that the mothers might be stressed and sacrificing their limited time. I made best use of the time I had in contact with the mothers and adopted a friendly and open demeanour to encourage them to freely express themselves and share their experiences and thoughts in a supportive environment.

Conclusion

Mothers caring for neurodivergent children experience significantly greater stressors in their everyday lives than mothers of neurotypical children. They routinely lack knowledge of how to best address the complex issues surrounding the care and development of their children. This knowledge gap also causes mothers to struggle to understand what the future may hold for them and their children. They commonly lack time to manage the

additional burdens that care for neurodiverse children brings. Time management techniques and approaches help them manage their time and care challenges, and much of this needs to be learned and developed by the mothers. The often-difficult choices that come with juggling time demands frequently lead to reduced and lost social connections, and opportunities, which are important to mothers' well-being and general mindfulness.

This study aimed to explore opportunities to develop practical interventions to support mothers caring for neurodivergent children. Using the psychological frameworks of COR and regulatory mode, this thesis provides a nuanced understanding of the needs and experiences of the mothers, and valuable insights for supporting their well-being in this context, proposing realistic, practical interventions.

Summary of chapters in the thesis

This thesis is comprised of six chapters, each of which is described below.

Chapter 1: Introduction. This chapter presents a synopsis of the rationale for this thesis and provides a summary of related literature. It considers the importance of the phenomenon investigated and the issues faced by parents caring for neurodivergent children. It provides a summary of the background, context, and originality of the study. The research methodology, method, research journey, and my approach as the researcher are summarised.

Chapter 2: Literature review. A critical review of the existing relevant literature considers the two psychological frameworks of conservation of resources theory, and assessment and locomotion within regulatory mode. These two frameworks are considered both theoretically and contextually. I review prior literature surrounding parents caring for neurodivergent children, and children with other long-term illnesses, to understand the predominant stressors and challenges faced by parents. I explore the pertinent aspects of the theoretical and conceptual models of COR and regulatory mode as they apply to mothers caring for neurodivergent children and suggest ways in which the two psychological frameworks may work together, considering the aim of this study.

Chapter 3: Methodology. This chapter explores my position as a researcher and outlines the research method and the design that I followed in this research. I evaluate my research approach and method and outline the specific types of analysis I used to help inform

subsequent chapters. I explain my approach to the participants and the interviews to optimise the details of the data gathered. The process for coding and theme generation in both NVivo and Excel, based on Braun and Clark (2006), is explained before presenting the findings in Chapter 4. I first explain the method used for collecting data using NVivo and then Excel.

Chapter 4: Findings. In the findings chapter, I provide details of my analysis of the data from my semi-structured interviews with the participants. I explain the findings as they relate to each research question from one to 5. I make extensive use of participant quotes to help explain and clarify the outcomes of my analysis. I conclude this chapter by summarising how each research question can be collectively considered to address the aim of this study.

Chapter 5: Discussion. In this chapter, I explore my research findings by comparing them with my literature review. The results of my analysis are evaluated, and either verified or contested through discussion and review. As in the previous chapter, I consider each research question from one to 5, which conclude with a proposal for practical interventions and approaches to support mothers caring or neurodivergent children. The results from the research questions are summarised in the final section of the chapter.

Chapter 6: Contribution to knowledge and practice. This chapter provides a conclusion to my thesis. It sets out the contribution that my research provides for mothers caring for neurodivergent children and summarises the application of the psychological frameworks of conservation of resources and assessment and locomotion within regulatory mode. The research questions, review of literature, methodology and method are considered. The practical application of the research is discussed, the study's limitations and opportunities for future research opportunities addressed. The chapter concludes with a review of the links between the two psychological frameworks.

Chapter 7: Professional learning as a researcher. This chapter reflects on my learning from the methodology and methods used, and the potential impact of this thesis and how its impact can be enhanced. It concludes with my personal reflections on the research journey.

2 Literature Review

Introduction

Providing long-term care for children can be demanding, often leading to routine stressors that impact resilience and capacity to cope. This can affect parents' motivation, resilience, wellbeing, and hope (Farkash et al., 2022; Morris and Pinelli, 2022). This study aimed to develop interventions for mothers caring for neurodivergent children to support their resilience and enhance their coping capacity. It sought to achieve this by drawing on the two psychological frameworks of conservation of resources theory (Hobfoll, 2001), and the self-regulatory orientations of assessment and locomotion (Kruglanski et al., 2000; Higgins et al., 2003) within Regulatory Mode (Carver and Scheier, 1990).

Reviewing the two psychological frameworks and determining whether a meaningful relationship between them can be established were key to this study. This chapter reviews the literature pertinent to this study's five research questions (RQs) which are set out in Figure 2-1. The chapter initially examines COR, then regulatory mode, and the literature on parents providing long-term care for their children, focusing where possible on neurodivergent children. The two psychological frameworks are first reviewed theoretically and then contextually.

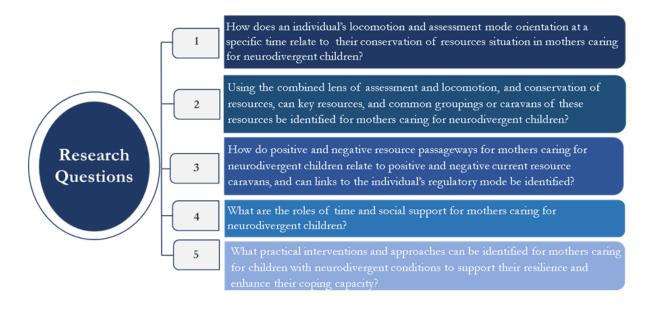


Figure 2-1: Research questions

Theoretical literature review

This chapter will next focus on the theory behind the two psychological frameworks of conservation of resources theory, and assessment and locomotion within regulatory mode.

2.1.1 Conservation of Resources (COR)Theory

COR theory states that people naturally try to protect, retain, obtain, and foster resources that they consider to be of personal value, to help maintain their well-being, goals, and success (Bell et al., 2020; Morris and Coley, 2004; Neveu et al., 2023; O'Brien et al., 2014), and to react to stressors (Hobfoll, 1989; ten Brummelhuis and Bakker, 2012). Individuals may experience stress if they lose, are at risk of losing, or fail to benefit from investing their resources (Hobfoll, 1989, 2001; Radford, 2024). Therefore, people are motivated to protect existing resources and acquire additional resources to maintain coping options and personal resilience (Hobfoll, 1989, 2001, 2012 Neveu et al., 2023). Resilience enhances an individual's capacity to endure and recover from difficult experiences, helping them to become more positive, robust, able, and stronger (Khu et al., 2019; Rolland and Walsh, 2006). These capabilities can be genetic, learned, or situational (Schneiderman et al. 2005), with resilience being resource preserving or enhancing (Bardol and Drogo, 2012).

Unlike other stress theories such as appraisal theory (Lazarus, 1999), COR theory concentrates on resource unpredictability as the principal stress mechanism, emphasising the objectivity of reality and observability of stressors (Hobfoll, 2001, 2011) rather than any personal situational appraisal. COR studies recognise that individuals with adequate resources are likely to perceive greater control through a sense of mastery and self-efficacy (Nicklin et al., 2019; Neveu et al., 2023). This results in a greater capacity for resource gain, less vulnerability to loss, and an improved capacity for resource protection (Neveu et al., 2023). Resources also have significant influence in resilience, and the capacity for hope (De Cuyper et al. 2012; Farkash et al., 2022). Recent COR studies have highlighted hope as a resource for mitigating stress and enhancing engagement while promoting and improving psychological well-being (Hamama and Levy, 2024; McGee et al., 2024; Snyder et al., 2020). Hope, linked to optimism and motivation, is also known to be a critical force for recovery from significant stressful events (Benight et al., 1999).

Managing time reduces stress (Alhasani and Orji, 2025), and regulatory mode associates time management with advantageous outcomes including satisfaction, performance, and stress in employees (Bedi and Sass, 2023). Pierro et al. (2018) noted that people with higher locomotor orientations adopt more effective time management strategies, with increased task-focus, reduce delays, and procrastination. This acknowledges Cornwell et al. (2019); Higgins et al. (2003); Kruglanski et al. (2000). It recognises the importance of perceived control for locomotors, for successful goal pursuit, achievement of effect, and change.

Resources were originally defined by Hobfoll (1989 p. 516), as "those objects, personal characteristics, conditions, or energies that are valued by the individual or that serve as a means for the attainment of these objectives, personal characteristics, conditions, or energies." Halbesleben et al., (2014: p. 5) subsequently proposed an alternative definition of "anything perceived by the individual to help attain his or her goals", suggesting a link between COR and regulatory mode.

Halbesleben et al., (2014) found that resource use can result in both positive and negative effect, such as when increased work-engagement leads to promotion, but also work-family conflict through reduced family-focus. As COR is commonly presented as a theory of stress and resilience, it is important to acknowledge both its positive and negative motivational aspects. Resources support personal motivation (Neveu et al., 2023) in part by fulfilling psychological needs for autonomy, competence, and relatedness (Deci and Ryan, 2008). Resource loss can lead to emotional exhaustion, and weaken self-identity and self-confidence, which can lead to depression (Chen et al., 2024; Hobfoll et al., 2003; Ren et al., 2025).

Benefits from resource use are not always immediate or responsive; and individuals may seek goals that provide long-term advantages. This can explain why people can take a long-term outlook on resource investment (Hobfoll, 1989), such as studying for professional qualifications, or investing for a 'rainy day', rather than immediate resource gain, for example sleeping-in over a weekend to catch up on sleep. The use of the concept of goals in COR theory (Halbesleben et al., 2014; Neveu et al., 2023) provides a link with regulatory mode, specifically an individual's progress toward goal achievement. It may highlight the importance of autonomous motivation and time as key imperatives in both frameworks

(Amato et al., 2014; Choy and Cheung, 2018; Lin et al., 2019; Tao and Jing, 2023). People may work towards multiple goals concurrently, gaining positive interim outcomes. Halbesleben et al., (2014), and Howard (2019) have highlighted the concept of micro-time interactions, which may balance positive and negative outcomes.

Looking now at what resources are, well-established literature has evolved to specify and classify resources (for example, Bourdieu, 1989; Coleman, 1988; Elder, 1988; Heinz, 2009; Hobfoll, 1989; Sewell, 1992; Ten Brummelhuis & Bakker, 2012). However, resources have generally been categorised into conditions, objects, personal characteristics, and energies (Hobfoll, 2001).

A study by Lu et al. (2021) examined entrepreneurs' resources. Lu et al. (2021) used two resource groups of personal and contextual resources (see Figure 2-2). Whilst these categorisations reflect previous classifications, they take a nuanced approach and may help us understand how resources are relevant for mothers caring for neurodivergent children. Lu et al. (2021) separated personal resources into two subgroups: personal characteristics, and energy resources. Personal resources were described as internal characteristics relating to the individual, whereas contextual resources related to the individual's social and physical situation.

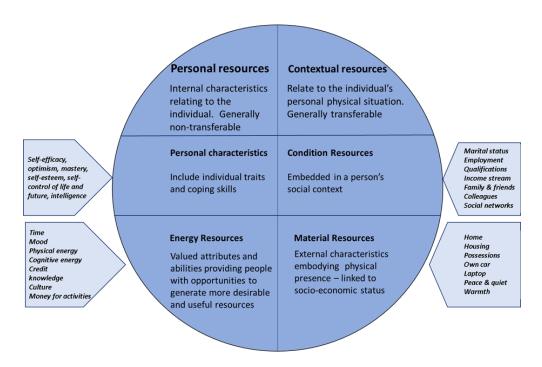


Figure 2-2: Resource groupings based on Lu et al. (2021)

Lu et al described personal resources as either internal characteristics, or energy resources. Personal characteristics include individual traits and coping skills such as self-efficacy, optimism, mastery, self-esteem, and self-control over life and the future. Energy resources include time, knowledge, and money. They are attributes and abilities which create capacity. Moving away from personal resources, contextual resources are either condition resources or material resources. Condition resources are embedded in an individual's social context, and include marital status, employment, family life, friends, colleagues, and social networks. Material resources are external characteristics embodying a physical presence and are likely to be linked to socioeconomic status; they include home, possessions, peace, and quiet.

COR studies have presumed that resources can be used to generate and collect additional resources in a continuous positive cycle, termed a resource-gain spiral (Hafstad et al., 2024; Sonnentag and Meier, 2024). People with reduced resource reservoirs may be less able to create and build resources and are more likely to drain their resource reservoirs, which is typified by a resource-loss spiral (ten Brummelhuis and Bakker, 2012). However, trait and adaptation theories suggest that chronic influences drive personal resource stability, along with work and family relationships, and this questions the concept of personal loss or gain spirals in the meso-term (Ford et al., 2023). Notwithstanding this, Smith et al. (2022) argue that people's resources are generally stable over time.

People may experience personal distress when they perceive a threat to, or loss of, their resources (Nicklin et al. 2019; Redford, 2024), or suffer resource instability (Bell et al., 2020). Individuals may experience stress when they need to balance competing pressures on their time. This may be from childcare demands, or work-family conflict, where resources can be compromised in the process of juggling work and family roles (Guo et al., 2024; Wang, 2024; Westman et al., 2004). Under such circumstances, people use their personal resources to reduce distress, but those with fewer resources may experience more detrimental psychosocial outcomes (Bell et al., 2020). COR theory notes that work-family conflict can lead to stress (Hakhmigari and Diamant, 2025; Kim et al 2024), whilst acknowledging that work-family interactions can also be beneficial (Lu et al. 2021; Chandran et al., 2024).

COR Principles and Corollaries

COR theory establishes four principles and three corollaries (Hobfoll and Lilly, 1993; Hobfoll et al., 2018; Radford, 2024). See Figure 2-2, and Figure 2-5.

The primary COR principle states that resource loss is disproportionately more salient than resource gain. Losses can occur quickly, and the effects can be significant throughout the period in which loss is experienced. Losses are considered in terms of their impact and magnitude and can be rapid, increasing in pace over time. It is recognised in COR theory that the scale and impetus of resource loss, making it a unique stress theory by considering momentum as a key factor. COR Principal No. 2 states that individuals invest their resources to combat resource loss, gain resources, or recover from losses (Hobfoll et al., 2018). This could include, for example, parents taking time off work to attend a meeting with a schoolteacher to improve the teachers' understanding of their child's problems.

Principle 3 states that when individuals experience significant resource loss, the personal value of their resources increase, and the need to replace or gain new resources increases in importance. The acquisition or retention of resources for individuals with low levels of resources can be particularly significant, as can the need and momentum to facilitate resource gain (Hobfoll et al., 2018). In regulatory mode, higher locomotors are likely to be most adept at resource preservation and gain, as locomotion should be the most likely orientation to achieve rapid replacement or generation of resources.

The fourth principle of COR theory, the desperation principle, states that individuals may adopt a defensive approach to the preservation of resources, which may result in irrational or aggressive behaviours to protect their well-being. This may include an individual stepping away to avoid a stressor, situational review, or seeking support to develop an alternative coping strategy. It could happen when a parent does not go into work because their children's situation or behaviour becomes too stressful, even though taking the day off may result in loss of much needed pay or may put them at risk of sanction. Protecting or building resources is objectively paramount (Hobfoll et al., 2018).

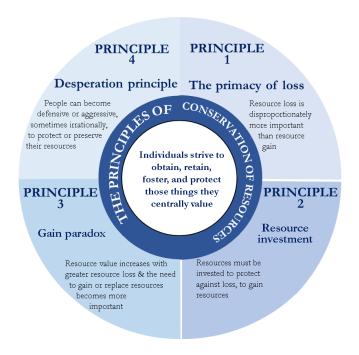


Figure 2-3: The Principles of Conservation of Resources - Hobfoll, 1999; Hobfoll et al., 2018

The corollaries of COR theory, reviewed by Hobfoll et al. (2018), are shown in Figure 2-4. Like the COR principles, corollaries help explain an individual's responses to personal stressors.

COROLLARY 1

Individuals with greater resource pools are more capable of gaining resources and less vulnerable to their loss. Individuals with fewer resources are less capable of gaining resources and more vulnerable to their loss.

COROLLARY 2

Resource loss cycles

The negative impact of resource loss is greater than that of resource gain, and individuals feel stressed when resources are reduced or lost. This stress can spiral as resources are further depleted or used to offset losses, resulting in an increase in both the intensity and momentum of the negative feelings.

COROLLARY 3

Resource gain cycles

Resource gain can also spiral, but the effect is slower and has less magnitude than resource loss.
Resource gain spirals tend to be less intense than loss spirals and typically develop at a slower pace.

Figure 2-4: Resource Corollaries - Chen et al. (2015) and Hobfoll et al. (2018)

The first corollary states that the possession, or a lack of resources, is integral to resilience and vulnerability. People with more resources are less vulnerable to loss and more

proficient in gain. Those with fewer resources are less able to gain resources and more likely to lose them.

Corollary No.2 describes the spiralling nature of resource loss, where the loss of resources is more powerful than their gain. As more resources are lost, increasingly fewer resources remain available for the regeneration or enhancement of personal resources. A resource loss spiral is likely to gain momentum, salience, and impact.

Corollary 3 states that resource gain is also spiralling in nature, but compared to resource loss, it is of less magnitude, with normally weaker and slower acting gains. Thus, the impact of resource loss increases when resource loss is greater, and individuals are more likely to act as losses increase, resulting in greater payback in more stressful situations.

This literature review will now consider the concept of resource caravans and passageways in COR theory

Resource Caravans and Passageways

COR theory contends that resources do not exist or act in a vacuum, or in isolation; rather, it assumes an active relationship between an individual's resources, the contexts in which they exist or are used, and the individual's environment (Neveu et al., 2023). The concept of resource caravans was developed by Hobfoll (2011) who argued that resources travel in caravans or packs and are grouped together (see Figure 2-5). Health resources are, for example, linked with psychological wellbeing (Heyman and Earle, 1999; Hauge et al., 2015). Self-esteem is mentioned by Hobfoll (2012, 2018) as a valued personal resource, one of three highly intercorrelated personal resources, alongside self-efficacy and optimism, that can "run in packs" (Hobfoll, 2012, p. 230). Linking COR with regulatory mode, these three resources are also related to effective task engagement (Xanthopoulou et al., 2009). Unlike assessors, a locomotor's focus on moving forward for goal achievement is linked to optimism, higher self-esteem, psychological vitality, and overall positivity (Kruglanski et al., 2000; Pierro et al., 2008).

Resource caravans

Resource caravan passageways

It is believed that resources do not function independently but exist and travel in groups.

An individual's resources are influenced by ecological conditions that either support, protect, enrich, and foster their resources, or obstruct, undermine, detract from, or impoverish them.

Figure 2-5: Resource caravans and resource caravan passageways (based on Chen et al., 2015; Hobfoll et al., 2018)

An individual's resources will ebb and flow, but they are amassed over time in what Hobfoll (2011) described as resource caravan passageways that support the development of resource caravans (Hobfoll and Hou, 2025). Individuals live within social networks, societies, and cultures, and they possess common resources which help maintain and foster their status, livelihood, and social connectedness. Resources are created in ecological circumstances which either limit and block or foster and nurture an individual's resource caravans through circumstances largely outside subjective control (Clissold et al., 2021; Hobfoll, 2012).

Pavlova (2021) used the term resource clusters rather than packs within the context of COR theory when referring to cumulative advantage and disadvantage (CAD) theory. COR theory and CAD are closely linked, and CAD helps explain the concepts of resource loss, gain, accumulation, and gain spirals (Hafstad et al., 2024; Sonnentag and Meier, 2024). CAD describes the evolving disparity in resources between individuals, their functioning, and well-being over time, although this differential can also be situational at critical life points (Dannefer, 2003; Elder, 1998; Johansson et al., 2007; O'Rand, 2009; Ye, 2024). This is because resource passageways, and cumulative advantage, or disadvantage, can influence a person's agency through their resource situation. The core of CAD theory is the Matthew effect (Merton, 1986) of (dis)advantage accumulation, where the rich become richer and the poor become poorer (Bask and Bask, 2015).

CAD assumes that better education leads to better jobs and earnings, and that early life advantages provide improved prospects for positive development. Conversely, people who experience relative disadvantages early in life are more likely to accumulate fewer resources and obtain fewer advantages later, affecting subsequent life situations and

opportunities in several life domains, including physical and mental health, and finances (Ferraro and Morton, 2018). COR theory (Hobfoll et al., 2018) posits that individuals with advantageous past lives develop and maintain greater, stable resource reserves, becoming rich in personal resources and external support. This leaves them better able to achieve positive outcomes in life and work (Hobfoll, 2012; Williams and Umberson, 2004). Recent studies have questioned this resolutely positive or negative trajectory concept, suggesting e.g. that individuals' life courses may change positively (Dai and Li, 2023; Jackson and Engleman, 2023; Johnson-Lawrence et al., 2015; Lee et al., 2023; Vilhena et al., 2019).

Like CAD, resource passageways combine diverse personal attributes and life experiences that affect and influence an individual's resource situation at a given time. Over a life course, an individual's resource caravans within their resource passageways result from cumulative advantages or disadvantages. These are linked to their ecology, social environment family and work (Hobfoll, 2011; Kaur et al., 2024), when adversities can lead to sustained, wide-ranging loss cycles (Hobfoll, 1991). Resource passageways can be characterised as the development and maintenance of an individual's steady state. The emphasis on resource caravans and passageways in COR supports our appreciation of resilience within social and cultural settings (Clissold et al., 2021), which is potentially relevant to parents caring for neurodiverse children within their specific environmental and cultural settings and resource caravan passageways. As Hobfoll et al. (2018, p.107) observed, social and environmental conditions create resilience or fragility, social adroitness, social awkwardness, tolerance, or intolerance among individuals exposed to (common) environments.

Time, a key limited resource

All activity requires time, but our time is limited (Bakker and Demerout, 2024; Yang et al., 2025). Time effects our resource conservation and generation, and self-regulation (Jansen et al., 2022; Mischel, 1973; Tiemouri et al., 2022), because the way we value our time will affect our approach to its use. Time scarcity can increase or decrease happiness (Kasser and Sheldon, 2009) because of its influence on our actions, and ultimately, it can affect our satisfaction, well-being, and contentment (Lee-Yoon and Whillans, 2019).

COR theory suggests has a basic tenet that individuals are driven to protect, regain, or obtain and foster valuable personal resources (Bell et al., 2020; Radford 2024). This requires time, itself a resource. Regulatory mode, with its focus on time as a resource incorporating flow and temporality, also recognises time as a key factor (De Voe and Pfeffer et al. 2011). Time is important not only for its temporal capacity, allowing movement from a current state to a desired future state (Kruglanski et al., 2016), but also for its impact on people's emotions, and attitudes about time, its perceived availability, and the how to make best use of it (Amato et al., 2019). Time pressures have been associated with self-esteem, personal energy, and more general resource depletion, leading to fatigue, impatience, emotional exhaustion and distress (Mühlenmeier et al., 2022; Pfeffer and Carney, 2018; Schilbach et al., 2023).

Time and regulatory mode

Regulatory mode orientations are influenced by, and over time, but can be stable and enduring over time (Lee-Yoon and Whillans, 2019; Whillans et al. 2016). Resource caravans are similarly influenced by context (Fan and Potočnik, 2021), but because they exist in ecological conditions which are established over time, they are likely to be relatively stable (Hobfoll, 2012, 2018). Mogilner et al. (2018) suggested that time helps people socialise, which can lead to increased happiness, and is not tied to a simple balance of current and future, but reflects life overall, which supports COR corollary 1, that individuals who have built-up greater resources, will be less vulnerable to resource loss, and more capable of resource gain.

Regulatory mode attributes financial value to time, for example, equating earning more money to the sacrifice of personal time which could be used in other ways. It acknowledges negative effects from poor time use, such as impatience, diminished meaning from work effort, and even psychological distress (Pfeffer and Carney, 2018; Schilbach et al., 2023). Regulatory mode also records both positive and negative social effects from valuing time like money, or less than money; negatives include reduced prosocial engagement and the adoption of more self-focused activities, and positives include happiness and social wellbeing (De-Voe and Pfeffer, 2010; Whillans and Dunn, 2015, 2019; Lock and Dunn, 2022).

The way that people evaluate time influences their emotions, attitudes, and behaviours, as well as having cognitive consequences (Lock and Dunn, 2022; Okada and Hoch, 2004; Soman, 2001). Amato et al. (2019) reported a relationship between the way people value time as a resource and their locomotion orientation. DeVoe and Pfeffer (2010) had noted that high locomotors reconcile their time investments and become impatient with ineffective use of their time, experiencing increased dissatisfaction and frustration from delays (DeVoe and House, 2012), procrastinating less as time becomes increasingly scarce (Fisher, 2001; Pierro et al., 2011). Other time-based behavioural consequences of high locomotion include increased multitasking (Kaufman-Scarborough and Lindquist, 1999; Pierro et al., 2013), with potentially reduced accuracy (Mauro et al., 2009).

Regulatory mode studies have proposed that valuing time as a resource may lead individuals to equate money to time, which DeVoe and Pfeffer, (2007b) suggested can be advantageous, because valuing time more than money can result in subjective well-being and happiness (Lee-Yoon and Whillans, 2019). Pfeffer and Carney (2018) found that ineffective time use was linked to impatience, psychological distress, and perceived poor meaning from work effort. Whillans et al. (2016) identified that 54% of people would prefer to give up money to create additional time. Individuals who value time more than money have been found to make decisions that enhance their available time, including moving closer to a workplace, or working reduced hours or improve subjective well-being and contentment (Hershfield et al., 2016; Whillans and Dunn, 2019). More time may help individuals socialise and consequently find greater happiness (Mogilner, 2010). Positive impacts of investing more time with others has also been shown to result from socialising with work colleagues (Whillans and Dunn, 2019).

Regulatory mode also recognises behavioural outcomes from considering time a resource, which is typical of a locomotion orientation. Examples in prior literature include increased use of time-saving equipment (Hessing, 1994), poor acceptance of delays, greater decisiveness, and impulsiveness in goal pursuit (Mauro et al., 2009). Other consequences include adopting a more speedy, but less exacting approach to task management (Payne et al., 1996), a polychronic approach (Kaufman-Scarborough and Lindquist, 1999), independent goal pursuit (Bélanger et al., 2015), an inclination to resolve conflicts with others (Webb et al., 2017), conscientiousness (Kelly and Johnson, 2005), delay reduction

(Lay and Schouwenburg, 1993), increased punctuality, and timely task completion (Frances-Smyth, 2006). Procrastination, typically an assessor trait is more likely in young male students, though there is no gender differentiation in young working adults Klingsieck, 2024).

Time and COR theory

Time is frequently mentioned in COR literature, where its function is generally associated with its temporal flow. Clissold et al. (2021) acknowledged time as a resource. Hayma et al. (2010) acknowledged the importance of time and its management for mothers. The control of available time is noted to be an important resource for supporting individual resilience, exhaustion, and work engagement (Forster et al., 2023 Schilbach et al., 2023). Hobfoll et al. (2018) observed that it is a resource that also acts as a resource and this is the period during which resource gain, regain, and loss occurs. According to Grawitch et al. (2010, p.133), time plays an important role in enabling the accomplishment of goals, whilst also being an enabler in effective goal management.

COR research on Finnish firefighters considered how long resources could remain effective, along with the time over which resource replenishment occurs (Airila et al., 2014). Other COR research has considered the period it takes for resources to act, such as the time between the awareness of a stressor and a response (Donald et al., 2016). The concept of developing capacity to deal with stressors over a period was mentioned by Hobfoll et al. (2018), such that challenges occur in the short-term, but decrease over time (Nohe et al., 2015). This is something potentially applicable to mothers caring for neurodivergent children. In a similar vein, Halbessleben et al. (2014) considered time-resource fluctuations and cycles in motivation, and Inceoglu et al. (2012) noted that, as motivation varies with age, with the value of resources change over time (Potocnik and Sonnentag, 2013). Overall, references to time in the COR literature are significantly focused on its temporality.

The resource of time becomes increasingly consequential in the context of its scarcity, such as when a deadline looms the value of time surges, and procrastination becomes increasingly less viable (Fischer, 2001). The mental balancing of time use (Di Santo et al., 2021), affects optimism, self-esteem, and positive emotions (Jansen et al., 2022). The emotional consequences of viewing time as a resource provides further associations

between regulatory mode and COR, such as when poor time use results in impatience (De Voe and Pfeffer, 2010), and frustrations from delay (DeVoe and House, 2012).

Social impacts

In COR research, Hobfoll (2011) considered that individuals were nested in the family, nested in the tribe, set within a social context. In self-regulation the constructive characteristics of positive social support are connected to increased engagement, and as locomotion orientation increases, social support from close others is welcomed, and goal engagement increases (Zee and Kumashiro, 2019). Hobfoll (2014) found an association between social support and engagement, and another COR study found the extent and quality of social connections significantly influenced physical and psychological functioning (Uchino et al. 1996).

Supportive social interactions are linked to improved emotional outcomes in stressful situations, and the importance of resource gain is recognised as significant for stress prevention and post-stress support (Hobfoll, 2003; Westman et al., 2004). Personal resilience is influenced by positive social contacts, and augmented by co-resources such as hardiness, self-efficacy, social esteem (Chen et al., 2015). As resource loss is dominant over resource gain (Hobfoll, 2014; Radford, 2024) the impact of traumatic events on engagement may be significantly linked to psychosocial resources and levels of social support, which suggests that social support is directly associated with positive engagement (Hobfoll et al., 2012).

People turn to close others for support with stressors (Kane et al., 2012; Qi and To, 2025), to deal with negative moods (Marigold et al., 2014), and to achieve challenging goals through practical help and advice (Feeney and Collins, 2014). Social support may support competence or self-esteem (Cohen and MacKay, 1985), or tangible resources or advice (Cohen and Wills, 1985; Simpson et al., 2007). Social and community resources can help parents navigate the care process (Babatunde and Akintola, 2023; Paintal and Aguayo, 2016; Shattnawi et al., 2012; Shaw et al., 2017). Support for parents and children can be derived from a range of individuals and sources both outside and inside work (Kraus et al., 2019; McTiernan et al., 2016).

People turn to close others for support with stressors (Kane et al., 2012; Qi and To, 2025), to deal with emotional exhaustion (Chen et al., 2024), negative moods (Marigold et al., 2014), and to achieve challenging goals through practical help and advice (Feeney and Collins, 2014). Social support may help competence, self-esteem, and wellbeing (Cohen and MacKay, 1985; Morris and Pinelli, 2022), or provide tangible resources or advice (Simpson et al., 2007). Social and community resources can help parents navigate the care process (Babatunde and Akintola, 2023; Paintal and Aguayo, 2016; Shattnawi et al., 2012; Shaw et al., 2017). Support for parents and children can be derived from a range of individuals and sources both outside and inside work (Kraus et al., 2019; McTiernan et al., 2016).

Crossover of resources

Frederickson (1998) argued that positive people are more likely to socialise, which increases their social capital, and lead to engagement, and resilience, helping resource building and more positive emotions (Frederickson, 2000). Crossover theory describes the transmission of strain and stress (or eustress) experienced by one individual to another Li et al., 2021; Westman, 2001). Resource caravan passageways and ecologies can support social relationships, and these can be reinforced through resource crossover (Chen et al., 2015). Crossover is an inter-individual process whereby resources, emotions, and experiences transfer positively or negatively within a social framework (Sha and Huang, 2024). The original model (Bolger et al., 1989) considered stress and psychological strain transfers, but the crossover model also includes the transmission of positive experiences and emotions, helping individuals build self-efficacy, wellbeing, positivity, and life (Cohn et al., 2009; Iyer et al., 2003; Heynet al., 2023; Threeboom et al., 2017; Westman, 2013). The crossover model may also support engagement through the crossover of resources, resulting in not only engagement but also resilience, flexibility, and better health (Chen et al., 2015). Crossover suggests people in close relationships may share strains and stressors, and positive aspects of their life and psychology (Sha and Huang, 2024; Song et al., 2008).

Closely associated with crossover is the broaden-and-build mechanism (Fredrickson, 1998, 2000), through which positive emotions signal the presence of well-being; helping people feel good, possibly predicting future well-being (Fredrickson and Joiner, 2018) which may increase their coping strategies and enhance resilience (Burns et al., 2008). Mikulincer and

Shaver (2022) found that perceived attachment security is associated with reduced prejudice, linking it to affiliate stigma. The concepts of crossover and broaden-and-build are likely to be relevant to parents providing care for neurodivergent children.

Interpersonal processes

Social support is derived from a variety of settings. It can have a significant influence on individuals (Blackmore et al., 2007) and has proved to be an effective moderator for preventing negative resource spirals (Meng and Choy, 2021). Social attachment, wherever it is found, can encourage individuals to seek close support from others (Hazan and Shaver, 1990) during actual or potential resource loss, perceived risk, or stress (Schirmer and Lopez, 2001). In work, colleague attachment can be a resource that can mediate potential and actual resource loss and negative outcomes, such as burnout (Karatepe, 2015). Meng and Choy (2021) found that in the workplace, colleagues' influence focussed on current resources rather than downstream, suggesting that early support may be optimal. Appropriate and timely social support helps people flourish and grasp opportunities to progress (Feeney and Collins, 2015). High locomotors are more amenable to, and profit more, from support, particularly affirmative support (Kumashiro et al., 2007). Di Santo et al. (2021) found that high locomotors tend towards future orientations and are more likely to pursue goals faster. Zee et al. (2019) identified that social support exchanges helped high locomotors with goal pursuit, whilst assessors find less benefit from overt support (Zee et al., 2018).

There are apparent links between COR and regulatory mode, although they are not explicit. An individual's predisposition to movement through change is a significant determinant of their orientation to time as a valued resource (Kruglanski et al., 2016). COR theory would suggest that such a predisposition will also influence an individual's approach to protecting, replacing, or generating personal resources. Although an individual's focus on personal resources will vary from time to time and situationally (Chen et al., 2015), if they are to progress or improve their situation, they must preserve, acquire, and develop their personal resources.

2.1.2 Self-regulation and Regulatory Mode

This chapter now looks at regulatory mode and will first clarify the terminology of selfregulation, regulatory modes, assessment and locomotion. Self-regulation (Mischel, 1973) is our capacity to regulate cognition and behaviours, and it acts as a coping tool to reduce negative effects (Schlaegel et al., 2022) whilst building emotional self-efficacy and psychological resilience to reconcile anxiety and stress (Li and Xie, 2020). An individual's self-control is linked to their subjective well-being, fluctuating daily and influencing life satisfaction through both positive and negative effects (Schmid et al., 2024). A selfregulatory structure lies behind our motivational actions (Carver and Scheier, 2017), selfregulation functioning through a negative feedback loop by which people can monitor their current state against achievement values (Wigfield, 2023). Divergence can lead individuals to take action to reduce the discrepancy (Zimmerman, 2023). Self-regulation therefore involves evaluation, comparison, and deliberation between different approaches and goals, to move (or not) from their current state to their chosen end state (Jansen et al., 2022; Tiemouri et al., 2022). Assessment and locomotion are linked to important personal outcomes, including emotion, motivation, psychological distress, a present or future focus, hope, and the differential valuation of time itself (Di Santo et al., 2021; Tiemouri et al., 2022; Whillans and Dunn, 2019).

Regulatory mode distinguishes between the two distinct orientations of assessment and locomotion within the self-regulatory systems (Kruglanski et al., 2000). Within goal pursuit, assessment is truth seeking and doing the right thing, and locomotion, is the control function (Higgins, 2012). Regulatory mode research typically focusses on either assessment or locomotion (Mathmann and Chylinski, 2022). However, the orientations are considered independent of each other, whilst having a modest relationship (Pierro et al., 2008, 2012). They work together to enable effective goal achievement (Orehek et al., 2017). However, individuals motivated to perform better have higher locomotor traits (Beylat et al., 2024; Loi et al., 2021), and locomotion may counter assessment traits (Lo Destro et al., 2017).

Assessment and locomotion therefore support, whilst also constraining each other (Higgins, 2012), with either having greater emphasis at a given time, or on a given phenomenon (Kruglanski et al., 2000; 2013). In balance, the two orientations are

complimentary, with imbalance leading to a temporal or predominant disposition toward one or the other (Gao et al., 2022). As such, they are discrete functional dimensions of any regulatory activity and they are emphasised both situationally, chronically, or contextually (Cavallo et al., 2016; Orehek et al. (2017).

Whether an orientation is chronic or situational a high assessor will concentrate on doing what they perceive is best, preferring to do nothing, if sub-optimal, or poorly thought-out actions may otherwise result (Jansen et al., 2022). Conversely, a high locomotor will be drawn to rapid, decisive action (Amato et al., 2019). Sok et al., (2016) found that locomotors were more proactive and organised, seeking progress and solutions. Indeed, "the essential nature of locomotion as a regulatory orientation involves simply initiating movement away from a current state to a new state without necessarily an ultimate destination, direction or place in mind" (Avnet and Higgins, 2003 p. 526). This appears to link to the persistent need to gather and conserve resources in COR theory, particularly during increasingly challenging or desperate personal situations (Hobfoll et al., 2018).

Regulatory Mode Postulates and Derivations

Over the years, studies on regulatory mode have recognised the impact of change on an individual's well-being. Research has identified positive and negative aspects of an assessment orientation. These include, thoughtful action, but also decision paralysis (Chen et al., 2018; Hughes and Scholer, 2017). Assessors can be more regretful, and less forgiving (Pierro et al., 2008. 2021). They are prone to anxiety, low self-esteem, depression, fear of invalidity, ruminative tendencies, discomfort, neuroticism, and ambiguity (Hong et al., 2004; Kruglanski et al., 2000). Conversely, locomotors are likely to have more optimism, hope, self-esteem, and psychological vitality, but have negative associations with depression, social anxiety, counterfactual thought, and regret (Di Santo et al., 2021; Kruglanski et al., 2000; Pierro et al., 2008, 2013a, b). De Carlo et al. (2014) also reported a positive association between an assessment orientation, strain, and burnout. Shalev and Sulkowski, (2009) found a negative association between locomotion orientation, burnout, and psychological strain. Locomotors can have higher self-optimism, be more decisive, and impulsive, prioritising expediency (Kanze et al., 2021; Komissarouk et al., 2019; Mauro, 2009). Figure 2-6 summarises these associations.

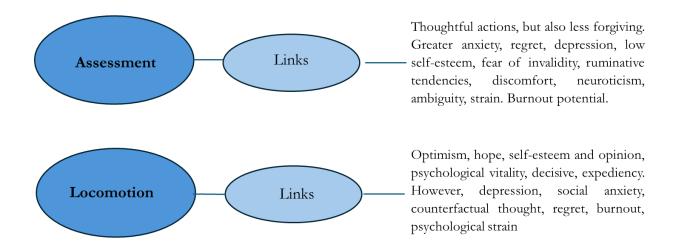


Figure 2-6: Regulatory postulate outcomes - based on Chen et al., (2018), De Carlo et al. (2014), Di Santo et al., (2021); Hong et al., (2004); Hughes and Scholer, (2017); Kanze et al., (2021); Komissarouk et al., (2019); Kruglanski et al. (2000), Mauro, (2009), Pierro et al. (2008, 2013, 2021), Shalev and Sulkowski, (2009)

Time is a key factor in regulatory mode, specifically for locomotors. A review of research relating to time as a resource acknowledged concerns about causality but identified a range of resource postulates and derivations relating to a locomotor trait and state (Kruglanski et al. 2016) (See Figure 2-7). While recent research has developed the postulates and derivations, Kruglanski (2016) helps us understand the effects of a regulatory mode foci.

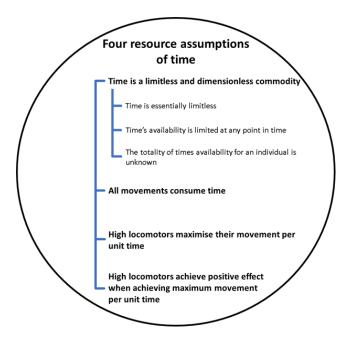


Figure 2-7: Four resource assumptions of time - based on Kruglanski et al. (2016)

Using his four resource assumptions Kruglanski et al. (2016) developed the five derivations of time relating to locomotors, depicted in Figure 2-8.

The first derivation of time is that a locomotion orientation should result in faster task performance, and this should lead individuals to undertake goals that can be achieved quickly, easily, and without interruption. Secondly, because goal achievement is paramount, unifinal rather than multifinal objectives will be prioritised. Locomotors should dislike more challenging, less achievable tasks. The third derivation recognises promptness in task initiation and action, highlighting locomotors goal-focus. Fourth, higher locomotors manage time more effectively, packing time with activities, prioritising, and not wasting the time they have. The fifth derivation is the positive effect that high locomotors derive from multitasking, with greater job satisfaction and negative stress (Kruglanski et al., 2016). High locomotion is significantly related to the efficient use of time, such that locomotors use less time than assessors to achieve objectives and perceive more successful use of time.

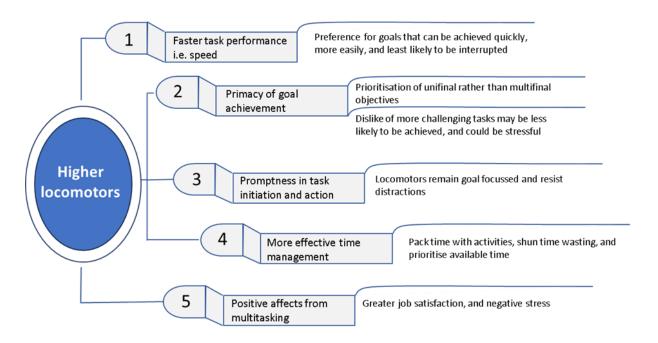


Figure 2-8: Resource derivations of locomotion - based on Kruglanski et al. (2016)

To gain goal achievement, locomotors may find it more acceptable to exchange longer-term rewards for less valuable, more immediate prizes, a form of temporal discounting (Lowenstein, et al., 2003). Temporal discounting is frequently perceived as a dysfunctional quality leading to impulsive decision-making. However, it can be explained as a rational adaptation to environmental uncertainties and resource limitations. This interpretation is consistent with the conception that short-term strategies may be advantageous in unpredictable settings. It is based on the inclination of individuals to devalue future rewards in favour of more immediate gratification. The tendency is more pronounced with uncertain or significantly delayed future rewards, rendering short-term strategies more advantageous (Villmoare et al., 2023).

The association suggests higher locomotors are future-oriented and their desire to achieve goals may enhance the value of the near rather than the far-future, prompting them to accept multiple lower-value short-term rewards, rather than waiting for more valuable longer-term rewards (Hobfoll et al., 1989). This concept resembles the COR theory assertion that, while individuals can take advantage of immediate or short-term resource gains, they may take a longer-term approach to their resource investment to secure a greater future return (Lin et al., 2019).

From the resource postulates and derivations, Kruglanski et al. (2016) established flow-postulates that higher locomotors are likely to exhibit. Overall, higher locomotors evaluate changes positively, exhibiting tendencies shown in Figure 2-9.

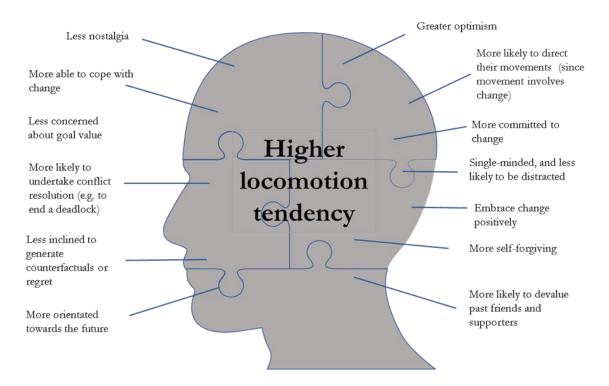


Figure 2-9: Higher locomotion flow-postulates – based on Kruglanski et al. (2016)

2.1.3 Impacts of neurodivergent childcare on parents

This chapter next focuses on the literature relating to the experiences of parents providing care for their neurodivergent children, specifically considering social support, work, employment, and income. It will conclude by considering health support mechanisms and their impacts. Literature related to parents caring for neurodivergent children and children with long-term illnesses are reviewed, as their impacts on parents are related.

Parents caring for neurodivergent children encounter unique challenges (Reddy et al., 2019) which are more significant than those faced by other parents (Cousineau, 2019; Pardo-Salamanca et al., 2024; Qi and To, 2025). Parents confront uncertainty about their children's future, and general stressors from relationship strains, which alongside financial challenges, can lead to physical exhaustion (Coffey, 2006). Additionally, they can experience anxiety (Amoria, 2020), depression, feelings of loss of control, hopelessness,

and in extremis, post-traumatic stress (Brown et al., 2008). The care burden is commonly focussed on mothers, who can experience stress and health issues, highlighting the importance of family support for maintaining and building resource reserves (Brennan et al., 2018; Silva et al., 2009; Payne et al., 2022). However, stress can affect an entire family, involving relationships, routines, activities, and time management (Smith and Kaye, 2012), and social networks (Gustafsson et al., 2002) and careers (Murray et al. 2007). Social networks are considered instrumental for neurodivergent children and their families (Mullins, 2024). Kish et al., (2018) summarised the parental challenges of caring for children with long-term illness into three foci of personal challenge, family and child, and workplace and work, with parents feeling uncertainty, frustrations, poor support from employers, and misunderstanding about their children's conditions.

Neurodiversity encompasses a range of conditions, including attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), cerebral palsy, and learning disabilities such as dyslexia and dyscalculia (Somerset and West Taunton, 2020). Although figures vary, the global prevalence of autism is estimated to be 1.04%, with approximately 700,000 individuals affected in the United Kingdom (UK Parliament Post, 2020). More broadly, 15% of the United Kingdom (UK) population is considered neurodivergent (ADHD Aware, 2024; Boland and Burgess, 2023). This suggests that one in seven people in the UK may be neurodivergent (Somerset and West Taunton, 2020). Recent studies suggest that 70% of children with autism will have one or more co-occurring neurodivergence (Lang et al., 2024). The number of individuals diagnosed with autism and ADHD has been increasing in the UK (Psychology Today, 2023).

Increased awareness of societal variations has shifted the emphasis towards inclusivity, with neurodivergent individuals being more vocal about their feelings and needs. A neurodiversity paradigm has been developed (Kapp et al., 2013) which recognises diversity in neurological and cognitive functioning (Singer, 2017), empowering neurodiverse people and moving the focus towards their talents and unique abilities. From a neurodiversity perspective, neurodiverse and neurotypical are distinct views of being and existing (Jaarsma and Welin, 2012), and neurodevelopmental variations may be better considered as conditions rather than disabilities.

Neurodiverse conditions commonly emerge during childhood and neurodivergent children often pose childcare challenges for parents, although issues may not be immediately attributed to neurodevelopmental conditions. Neurodivergent behaviours change but can persist throughout a child's adolescence and continue into adulthood (APA, 2023). As individuals, neurodivergent parents can continue to face struggles, dealing with stressors differently to non-neurodivergent parents (Dugdale et al., 2021). The proportion of parents with neurodiverse children who are themselves neurodiverse may not be uncommon (Dugdale et al., 2021). Non-academic sources suggest that an association is likely (Mueller, 2024), with possibly 77% of parents with a neurodivergent child being neurodivergent themselves (Pring, 2023).

The effects of neurodevelopmental conditions are diverse and require various approaches, support levels, and interventions. ASD is considered across a spectrum, and children typically experience behavioural issues, language difficulties, social deficits, hyperactivity, injury, aggression, irritability, ritualism, and non-compliance (Shepherd et al., 2018). ADHD symptoms include impulsivity, hyperactivity, inattention, being easily distracted, forgetful, talking excessively, difficulty staying focused, and fidgeting (Okyar and Görker, 2020). These effects commonly lead to problems with communication and social interaction, which can affect participation in occupational and social activities (Mahone et al., 2017).

Neurodivergent children have distinctive challenges and can struggle to participate in typical childhood activities compared to similarly aged neurotypical peers (Mullins, 2024; Ritzema et al., 2017; Sapre et al., 2025) and often require additional support. The children face obstacles that affect their own well-being and that of their families. Subsequent caregiver strain and reduced social connections owing to affiliate stigma or time constraints can negatively affect parents' well-being (Mikulincer and Shaver (2022); Scherer et al., 2019) and the benefits of social support networks (Bozkurt et al., 2019).

The quality of life (QoL) of caregivers of neurodivergent children may generally be lower than that of neurotypical children (Vaz, 2022; MacKenzie and Eack, 2022; Poole et al., 2024). Emotional, psychological, and close and wider family challenges are commonly reported, with parents experiencing poorer outcomes than parents of neurotypical children and children with disabilities (Padden and James, 2017; MacKenzie and Eack, 2022; Poole

et al., 2024). Neurodevelopmental children frequently present with challenging behaviours (Estes, 2009) which can lead to parental strain, anxiety, stress, and depression (Jellett et al., 2015). Parental stressors can develop when situational demands outstrip available resources (Webster-Stratton, 1990), with higher parental stress worsening some neurodevelopmental behaviours (Lecavlier et al., 2006). This can further stress parents, increasing child stress (Hastings, 2003; Benson and Karlof, 2009), and can affect parent-child relationships and potentially lead to maladaptive and poor parenting (Van Steijn et al. 2014).

The severity and detail of children's neurodivergent symptoms may be a significant predictor of caregiver stress (Lecavalier et al., 2006; Pardo-Salamanca et al., 2024), although earlier studies by Falk et al. (2014) and Minnes et al. (2015) did not find this to be the case. Research by Cousin and Hazen (2014) suggested that parental stress was linked not to diagnosis, but to the responsibility involved in managing the child's care and the parents' psychological ability to adjust. Caregiver stress may instead be associated with the negative consequences of parenting challenges which studies into ASD have found to be linked to social stigma, financial concerns, and challenges from dealing with formal support agencies (Serrata, 2012; Bonis and Swain, 2016; Mikulincer and Shaver (2022); Pilapil et al., 2017).

Acknowledging the expertise of parents in their own children's lives (Cuenca-Sanchez et al., 2024), various studies have reported that effective support packages designed to meet parents needs can address many of the negative effects on parents associated with poor professional guidance, diagnostic processes, and limited carer understanding (Derguy et al., 2015; Tellegen and Saunders, 2014; Zand et al., 2018; Zuurmond et al., 2018). Beyond the burdens of neurodevelopmental childcare, parents can experience reduced family, and social support, and apprehensions about the future (Vaz et al., 2022).

Parents of neurodivergent children frequently face greater anxiety, anger, depression, and stress (Zabotsky et al., 2013; Hayes and Watson, 2013; Pardo-Salamanca et al., 2024) and consequently adopt coping behaviours. Parents may adopt positive coping strategies, or they may adopt potentially harmful active avoidance approaches with less positive behaviours to deal with their experiences (Hudson, 2016; Lai and Oei, 2014; Sarria and Pozo, 2017). Self-compassion, routines, and social support can reduce stress and depression, and improve wellbeing (Neff and Faso, 2015; Pardo-Salamanca et al., 2024;

Schlebusch, 2015). Individuals are noted to be more able to discern meaning through perception, empathy and confidence (Altiere and Kluge, 2009; Fenuster, 2014; Matenge, 2013; Predescu and Sipos, 2013).

The complementary effects of positive emotions, including constructive attachments and gratitude through the creation of positive resource gain spirals have been acknowledged through the concepts of crossover and broaden and build, for enhancing wellbeing (Wei et al., 2021). The additional care and advocacy demand inherent in supporting neurodivergent children can lead to perceived and practical time pressures requiring concessions to important life satisfaction activities such as relaxation time, self-care, social interaction, and career development, all of which can negatively affect caregivers' QoL and well-being (Estes, 2009; Khanna, 2011; Vasilopoulou and Nisbet, 2016).

Support

Prior research has focussed on improving child behaviours rather than helping parents (Tellegen and Saunders, 2013; Skotarczak and Lee, 2015). Studies have identified greater depression and anxiety in parents of children with chronic conditions than in parents of healthy children (Asbury et al., 2021; Cohn et al., 2020). Findings on access to healthcare by parents are contradictory. Shah et al. (2012) found that mothers of chronically ill children accessed mental health services 22% more than mothers of unaffected children, with 59% greater use of psychotherapy by the mothers. The literature on the efficacy of psychological interventions for parents of chronically ill children is contradictory. A Cochrane review of psychological therapies provided little support for the benefits of interventions for caregivers' mental health (Eccleston et al., 2015) but did support the use of problem-solving therapies. Compassion Focused Therapy (CFT) is advocated as an intervention for elevated self-criticism and shame and may be appropriate for directed selfhelp with parents caring for autistic children; further work on its feasibility and effectiveness is needed (Kemp, 2024). Caregivers of children with diabetes, another longterm condition affecting children, appeared to help if their uncertainties were managed (Hoff et al., 2005). Recent academic and practical publications are increasingly offering practical advice and support (Knightsmith., 2024; McCarthy, 2024; Riall, 2023).

The literature suggests that support programmes can develop resilience and coping skills and improve lives of parents caring for neurodivergent children (Amsbary and Able, 2023; Guralnick, 2023; McConkey et al., 2023; Mullan et al., 2021). The conflicting outcomes from parental support initiatives noted in the literature suggests the need for carefully tailored and individualised support, rather than a 'one-size-fits-all' approach (D'Arcy et al., 2021; Shepherd et al., 2018; Tollan et al., 2023).

The responsibilities of parents caring for children with chronic conditions can affect the resource ecology of the entire family, potentially depleting their time, social, and financial resources. Early research showedResearch showed that social support can lead to better outcomes in stressful situations (Chen et al., 2024; Vaux, 1988). Social and family support are frequently acknowledged in studies on neurodivergence for their positive impacts on individuals' wellbeing and life-satisfaction (Halstead et al., 2018; Lovel and Weatherell, 2019).

Kuo et al. (2011) found that families of children with complex medical conditions had little or no expectation of help from family and friends, possibly because caregiver parents did not have energy or time to associate with others (Caicedo, 2014). Brown et al. (2008) suggested that this is more likely to occur with single parents. For parents of neurodivergent children, negative effects linked to poor support and social stigma limited social activities and have been associated with discrimination (Reddy et al., 2019; Zuurmond, 2019).

Accepting help from family and friends is considered a positive, adaptive coping strategy (Fairfax et al., 2019), and is important for parents to sustain normality, providing them with relief from stressors (Thyen et al., 1999). The development and conservation of effective social ties are linked to our capacity to foster social connections for self-regulation (Lee-Yoon, and Whillans, 2019), and this can benefit others through conforming to social norms (Vohs and Ciarocco, 2004).

There is increasingly innovative use of assistive technologies by services supporting parents providing care for children with neurodivergent conditions. Studies have focussed on the health and education sectors.

The digital environment incorporates a broad and increasing range of assistive technologies for neurodivergent children, and by extension, or separately, for their parents. Apps et al. (2024) found that parents of children with complex needs endorse the use of digital technologies such as computers and telephone rather than face-to-face contact and written communication, to support their child's rehabilitation. Parents found them useful and supportive, so long as in-person therapist contact was maintained. A study of parents caring for children with disabilities in mainstream education considered the effectiveness of more advanced assistive technologies (Jakovchevska et al., 2024). The parents in that study generally had positive views on the potential of assistive technologies for promoting inclusion and improving educational outcomes for children with disabilities. However, they recognised obstacles including affordability, accessibility, and adequate training impeded optimal application The importance of human input for assistive technologies is reinforced by Kohli et al. (2025) who consider technology to be an empowering tool, rather than a replacement for human involvement in ASD recognition and involvement. Cerero et al. (2024) reinforce the importance of parental involvement in the use of assistive technologies, including creating a regulated home environment and developing proactive relationships with school staff.

Cerero et al. (2024) highlighted challenges to success, including limited ASD-specific training for teachers and parents, restricted school resources, and communication barriers. These findings reinforce Jakovchevska et al. (2024) comment on the need for constructive directed interventions by policymakers, educators, and practitioners to address the difficulties of creating accessibility and efficacy in education. AI technologies have been studied for their effectiveness in supporting parenting behaviour and child-well-being (Petsolari et al., 2024). Considerable research and attention have been paid to the use of technology in education. Drigas et al. (2023) studied information and communications technologies (ICT) in education, specifically, their effectiveness and productivity, for enabling and improving assessment, intervention and education through computers, tablets and mobiles. ICT applications, AI, robotics and games support can enhance traditional educational methods, whilst also creating a more friendly and enjoyable experience (Drigas et al. (2023).

Artificial Intelligence (AI) and related technologies increasingly provide valuable assistance to individuals with neurodivergent conditions. Vashisht and Jatain (2023) assessed a computer aided approach for diagnosing neurodevelopmental disorders employing mathematical and deep learning models. Yahya et al. (2024) found that AI-based robot therapy is increasingly used to meet the needs of children with neurodivergences. Robot platforms utilising AI are used to engage with individuals with ASD to support therapeutic interventions and assessments. AI and robotic integration therapy offers promise for improving the enhancing the quality of life for neurodivergent children.

Current technologies can support not just assessment, but also monitoring, and treatment of neurodevelopmental disorders, education, learning, communication, and independence through personalised support (Bertachini et al., 2024). Studies have also recognised the potential for chatbots to provide for bespoke learning needs of neurodiverse students to increase competency and enhance autonomy, and relatedness (Mmukherjee, 2025). Bertachini et al. (2024) looked at the application of social robotics (human/robot interactions) using a humanoid robot (Pepper robot) connected to Chat-GPT (AI) for ASD and ADHD conditions. McFayden et al., (2024) found that although Chat-GPT-4 had limitations, it provided precise, accurate, and generally understandable information about autism, with prospects for effective improvements. Pepper robot provided instantaneous discourse, emotional recognition capacity, and visual stimuli to assist with behavioural interventions for children with ADHD. Developments of social robotics may provide increasingly effective interventions and tools to support individuals with ASD through social interactions and broader developmental elements.

Bertachini et al. (2024) concluded that future advancements may concentrate on developing personalised adaptive interaction frameworks tailored to meet the specific needs, preferences, and objectives of individuals. These frameworks could enhance emotional understanding, improving the machine ability to perceive, interpret, and respond to emotional cues of individuals with ASD (and presumably their parents). Forthcoming implementations may incorporate gesture recognition, haptic feedback, and mechanisms for tracking and monitoring the progress of individuals with ASD over time. This will facilitate ongoing assessment of communication skills, social interactions, and problem-solving abilities. Furthermore, collaboration with therapy and education professionals

could facilitate the implementation of evidence-based practices and therapeutic or educational programs (Bertachini et al., 2024).

Chen (2023) refers to "EdTech"; contemporary educational tools designed for neurodivergent children, which help to support their attention, executive functioning, and memory using reminders, timers, and study aids. Interactive activities and visual aids can enhance student engagement and comprehension while providing teachers with real-time feedback. EdTech, in the form of interactive multimedia tools and gamification, is also effective in increasing engagement for students with ASD, assisting them in maintaining focus and developing social and communication skills. Virtual avatars can offer students clear social cues, thereby granting them greater control over their self-expression (Chen, 2023). Moore (2024) reported on Lumio, a cloud-based lesson portal which is specifically designed for remote teaching. It incorporates annotation, break-out rooms, and teamwork to accommodate individualised student needs. Lumio and similar new platforms specifically support SEN-related accessibility characteristics, helping neurodivergent individuals' study and engage by accommodating their needs and preferences (Moore, 2024).

Chatbots have been found to provide valuable informational and emotional support for parents during preconception, pregnancy, and postpartum periods (Chua et al., 2023). It is reasonable to conclude that similar innovations could support parents caring for neurodivergent children. Indeed, the creation of multidisciplinary chatbot development teams to progress the scope of chatbot-delivered health programmes for more diverse populations, as well as in chatbot functionality, and training for healthcare providers, were recommended. Such developments promise positive and easily accessible developments for both neurodivergent children and their parents. The continued development and introduction of technological solutions will be critical in delivering much needed resources and support to families caring for neurodivergent children.

Work, Employment, and finance

The conflict between work and family faced by working parents of neurodivergent children exposes complexities in balancing caregiving responsibilities with career ambitions (Balachandran and Bhuvaneswari, 2024). Parents require balance between caregiving

responsibilities and participation in meaningful activities to maintain quality of life (Davy et al., 2023). Recent studies highlight the value placed on work-family balance and work culture by these parents (Stevens et al., 2024). However, the need for balance is key to life satisfaction, as well as the quality of mother-child interactions, which can be affected by increased workhours (Agostinelli and Sorrent, 2021; Bastian and Lochner, 2020). Fan et al. (2021) noted the need for an effective combination of time and personal finance for family and childcare satisfaction in mothers caring for children with long-term illnesses. In the COR literature, Grawitch et al. (2010) referred to work-life balance as a person's ideal use of their resources to deal with stressors and ensure effectiveness in work and nonwork roles. Maintenance of family income, work hours, and careers are commonly studied in parents providing care for children with long-term needs, although research offers limited advice on practical support for caregivers in work settings (Doyle, 2020). Brown et al. (2008) suggested a strong association between a child's health and family income, as employment is not always straightforward for parents caring for children with long-term needs. Kish et al., (2018) found that caregiver responsibilities rarely resulted in parents ceasing work, but did lead to work adjustments which led to financial challenges affecting their quality-of-life. This was particularly true for single parents (Thomas and Sawhill, 2005).

A perceived lack of time can lead mothers to perceive physical and psychological depletion (Akram and Akram, 2019). Easterly et al. (2022) found parents of children with special healthcare needs were more likely to sacrifice employment in some way, and Kuo, et al. (2011) reported that one parent had stopped work due to their children's needs in 54% of their sample, and over 60% had changed their employment. Montgomery et al. (2002) suggested that 30% of their sample had experienced job reduction with financial deterioration through caring for chronically ill children. Conversely, Loprest and Davidoff (2004) found no significant association between working hours and caring for chronically sick children in low-income families.

Support techniques such as mindfulness, acceptance commitment therapy, and general parent training and coaching have been shown to help parents caring for neurodivergent children (Li et al., 2024; Yesilkaya et al., 2024). They can improve negative psychological effects, reduce distress, and develop coping skills to deal with stressors (Izadi-Mazidi et al.,

2015; Iadarola et al., 2018; Threeboom et al., 2017). Mindfulness can also help in the work context to improve motivation and performance (Hyland et al, 2015; Kroon et al, 2015). Mindfulness can vary through situational factors (Reina and Kudesia, 2020) and is acknowledged for its capacity to support and benefit individuals' self-regulation (Isbel and Mahar, 2015). This suggests mindfulness may be a positive component for parents caring for neurodivergent children. An important component of mindfulness is its capacity to nurture compassion for oneself and others, to acknowledge feelings, understand, and relieve suffering (Goets et al., 2010; Kemp, 2024). Compassion can reduce social isolation through connection (Neff and Faso, 2015). It can support the development of personal resources to protect against the negative psychological effects of stressors (Seppala et al., 2013).

Stressors can result from efforts to balance family life responsibilities and work commitments (Sellmaier, 2021). A Rockwool Foundation Research Unit study (2010) suggested parental stress was linked to parental ambitions for a sick child rather than to consequences of the hours they worked. The 2010 Rockwool study reasoned that income and time spent with children were antithetical, with lower income resulting in more time spent with children, and vice versa. Work provides income (George, 2011), as well as creating opportunities for social associations and routines (Van Campen and Cardol, 2009). However, it can result in home-work conflict, affect work performance (Schaufelli and Tarris, 2014), and parental health and well-being (Tibboel et al., 2011).

Research on the current impact of work culture on parent carers is scant. However, studies do consider work and neurodivergent employees, which appears to be relevant, not least because parents of neurodivergent children can themselves be neurodivergent. Davy et al. (2023) identified employment as a meaningful activity and one of several key themes linked to how parenting an autistic child impacts the primary caregiver's life. The need for employers to be aware of how time demands, work culture and managerial leadership and support can impact this more challenged group of employees are acknowledged (Stevens et al., 2024). As parents of neurodivergent children can themselves be neurodivergent, it is also important for employers to embrace inclusive practices, and acknowledge the challenges and opportunities faced by neurodivergent people. Help can be provided

through supportive practices including inclusive work environments that accommodate the neurodivergent worker and their views (Kaaria et al., 2024; Thorpe al., 2024).

Employees are commonly expected to commit to work needs, and even prioritise them (Blackwell, 2024). This can be challenging for parents caring for neurodivergent children. Effective human resource practices and policies acknowledge the significance of listening, communication, empathy, and adaptability in empowering individuals with neurodivergent conditions (Kaaria et al., 2024; Thorpe et al., 2024). This approach may offer insights into supporting and empowering parents of neurodivergent children within the workplace. Recent research underscores the importance of employment policies that consider a wide range of factors impacting all employees across an organization (Blackwell, 2024). Gore et al. (2023) identified three themes in their study of autistic working mothers. First, work provides purpose and supports well-being. Second, it presents challenges in balancing caregiving and work, including feelings of guilt associated with working and issues related to part-time employment. Third, there is a lack of understanding of mothers' challenges due to assumptions that they are coping and may appear fine. Gore et al. (2023) suggest that their findings regarding autistic working mothers are also likely to be applicable to non-autistic working mothers. Understanding whole workforce needs can lead to tailored support systems that foster inclusive workplace cultures, but leadership is essential to accommodate the diverse needs of parents alongside their work responsibilities (Stevens et al., 2024).

Individuals with neurodivergent conditions may encounter challenges with conventional in-person work environments, which can lead to problems related to the environment and sensory stimuli (LeFevre-Levy et al., 2023). Hennekam et al. (2024) identified a prevalent perceived workplace pressure on neurodivergent working adults to conform to neurotypical norms. This, linked to the stigma associated with their condition can compel them to adopt personal coping strategies to present themselves as neurotypical. The study further highlighted social class as a factor that exacerbates inequalities among individuals. These findings have implications for education and industry, underscoring the need to foster more inclusive environments for neurodivergent individuals.

Kalmanovich-Cohen and Stanton (2023) observed that remote work can offer benefits to all employees by enhancing flexibility and reducing commuting, stress, and work–family conflict. Specifically, it can enhance job satisfaction and yield positive outcomes for organisations, while being particularly advantageous for employees with neurodiversity (Kalmanovich-Cohen and Stanton, 2023). Offering a remote work option may result in higher retention rates by supporting and empowering neurodivergent workers and parents caring for neurodivergent children. Full realisation of the benefits of such approaches, requires an organisational shift towards a social model of neurodiversity which emphases interindividual variability in traits and their potential advantages, rather than focusing solely on the associated challenges (LeFevre-Levy et al., 2023).

Parents consider that working from home is a way to achieve both work and childcare needs (Miktas, 2024). A US study during the Covid pandemic by Fan and Moen (2024) confirmed that remote working decreased parental stress compared to those attending the workplace, most notably in mothers. Studying mothers of children with neuropsychiatric disabilities during the Covid Pandemic, a study by Lindgren and Nelson, (2024) found that some families had limited changes to already family-cantered lives. This is likely to be the case for mothers caring for neurodivergent children. Other studies reinforce the need to be aware of the preferences of individuals to effectively support all employees rather than adopting a one-size-fits-all approach Brookes et al. (2024). Their study found that neurodivergent workers both benefited and were challenged by working from home. Challenges included reduced structure due to new or lost routines, whilst benefits were experienced through reduced need for "masking", and in-person social contact, and the use of technology. Braniki et al (2024) found that flexible and homeworking practices can improve employment outcomes for neurodivergent individuals, and by default, parents caring for neurodivergent children.

Parry (2025) suggests that remote work flexibility during COVID-19 led to gendered patterns where fathers' work was prioritised over mothers, alongside the mother's caregiving responsibilities. Study findings suggest that fathers' work is prioritised, with mothers' work being fragmented and dispersed as the primary caregivers. This has led to women self-exploiting themselves in the domestic environment in a work-centred society of dual-earner parents with young children. The role of human resource management and need for clear supportive policies and practice is clear.

2.1.4 Exploring the literature gaps

The aim of this study was to develop initiatives to support mothers caring for neurodivergent children using COR, and assessment and locomotion within regulatory mode. No papers could be found in COR theory combining resource states or caravans and the regulatory mode orientations of assessment or locomotion. There also appears to be negligible research in regulatory mode considering explicit links between personal resources and an individual's resource situation. This represents a gap in the literature. Any association must be assumed through mention of resources, such that either an assessor or locomotor orientation may be presumed to have a greater capacity to create, retain, or protect their resources. Although regulatory mode studies frequently use the term resources, it is used in its broadest sense; as a supply or reserve of personal capacities, rather than referring to the complexities of resources and the principles and corollaries developed within the COR theory. This study therefore sought to gain greater understanding of how COR and regulatory mode theories may be associated. Additionally, I was unable to find studies in the fields of COR or regulatory mode that examined how the two domains relate to mothers caring for neurodivergent children. Although previous studies have pointed to the potential application of each theory to such mothers, it is evident that there is a gap in the literature concerning whether and how the two theories can be used to support mothers caring for neurodivergent children.

This chapter now looks at the gaps through both a COR, and regulatory mode lens.

Conservation of Resources links with regulatory mode

COR research has fallen short of effectively researching both regulatory mode and personal resources, and no studies can be identified that jointly research the two constructs.

Tesi (2021) examined regulatory mode and the job demands-resources (JD-R) model, noting the importance of job and personal resources on goal achievement. The study referenced specific personal and work resources commonly cited in COR theory. A key finding was that locomotion was associated with higher work engagement, which was attributed to the use of personal resources. However, the focus was on regulatory mode theory and the JD-R model, not COR. Tesi did not expand on his 2021 study theme, although he later considered resources through job demands, work constraints, and

inhibition of valued goal achievement, again, within the context of the JD-R model (Tesi et al., 2024).

Halbesleben et al. (2014) proposed that self-regulation might determine how a resource trajectory becomes a loss or gain cycle. They suggested that acquiring new resources may increase goal achievement likelihood more than using existing ones without referencing specific resources. Halbesleben later co-authored an article on regulatory focus and resource gain and loss cycles, but did not progress his 2014 study (Paustian-Underdahl et al., 2023). Similarly, Nizri et al. (2024) focused on regulatory flexibility as an internal personal resource without referencing COR Theory, assessment, or locomotion.

Aside from Tesi (2021) and Halbesleben (2014), COR research often refers to self-regulation in its broad sense as an individual having control of or regulating their situation (Carver and Scheier, 1990; 1998). However, studies linking the regulatory mode orientations of assessment and locomotion could not be found in COR research. Lam et al. (2017) refers to 'self-regulation' when considering that employees adopt defensive positions in resource investment strategies as their resource availability decreases. Similarly, Kakavand et al. (2019) found that corrupt workplace behaviour was a response to perceived threats to employees' work resources and was connected to their self-regulation to achieve resource preservation goals. Kocalvent et al. (2013) referred to, but did not detail, self-regulatory resources in a generalised stress model based on Lazarus and Folkman's transactional model of stress (Biggs et al., 2017).

Lazarus (1993) argued that people cope better when they modify their thoughts, behaviours, and emotions through self-regulation using problem-solving or emotion-focused modification. More recently, Diestel (2022) examined self-control demands to help employees cope with job demands that require self-regulation choices, and Gerpott et al. (2022) suggested that self-regulation consumes individuals' regulatory resources, resulting in ego depletion.

Regulatory mode links with conservation of resources

Numerous studies have referred to time as a resource, and other resources have also been referenced. Kruglanski et al. (2000) refer to psychological resources, and Lucidi et al. (2016)

mention optimism and vitality. However, the link between regulatory mode research with personal resources and an individual's resource situation remains relatively rudimentary.

Amato et al. (2019) may provide the most significant link between regulatory mode and COR theory, referencing time as a resource. Looking specifically at time as an enabler for movement and change, Amato et al. (2019) highlighted the value that locomotors place on time to progress and achieve goals. Despite their narrow focus on time, Amato et al. established it as a resource for goal achievement in regulatory mode studies. There is no reference by Amato et al. (2019) to time being part of a resource reservoir, as the focus on time is specific to goal achievement, emphasising its temporality value. Lee-Yoon and Whillans, (2019) noted that time is a finite, precious, and scarce resource, suggesting that the way we value our time influences our happiness and improves or weakens our well-being.

These time-related behaviours may directly and indirectly impact an individual's resource reservoirs, although associations in the regulatory mode literature fall short of proposing a direct relationship with COR theory. Amato et al. (2019) suggests the potential for further associations between the two frameworks, recommending future research considers resources other than time, such as money. However, reviewing subsequent publications by Amato et al. (2019), it does not appear that the proposal was taken forward. Like Amato et al. (2019), Kruglanski et al. (2016) viewed time generically as a resource essential to attain things that are valuable and measurable, making it a quantifiable possession. Sheldon and Kasser (2008) also looked at people who consider time a scarce resource, suggesting that thoughts of scarcity decreased happiness, although other research contradicts this finding, finding that it can increase happiness (Kurtz, 2008; Layous et al., 2017).

Research by Kruglanski et al. (2000) noted that using resources may leave assessors with fewer buffers to counter difficulties. Lucidi et al. (2016) examined the potential stress development in locomotors if they continuously mobilised personal resources such as optimism and vitality for goal pursuit, noting their protective value. Both studies have recognised the importance of resources in regulatory mode orientations. Kruglanski et al. (2000, p. 794) acknowledges that "psychological resources can help initiate and maintain goal-related movement in a straightforward and direct manner". Therefore, regulatory

mode research has considered resources more broadly than the COR framework, suggesting that resource scarcity in a generic sense is important (Shah et al., 2012; 2015).

Despite the apparent lack of prior research links between the two psychological frameworks established in this literature review, it is reasonable to associate a person's resource situation with their regulatory mode. An individual's assessment or locomotion orientation can stem from a predisposition to move to a particular state or result from situational factors such that an individual may take different actions in different situations or times (Kruglanski et al., 2016). High locomotors move rapidly from one state to another, often simply for the sake of movement, possibly without specific goals. This suggests a link to the desperation concept, that is, the 4th COR Principle which states that an individual's action may be illogical, but the result of an overwhelming need to act and generate change.

To summarise, time is recognised as a key resource in COR theory and is a crucial component within regulatory mode, supporting appraisal, judgment, and critical thought. Despite the apparent lack of joint research on regulatory mode orientation and COR theory, links between the two frameworks are evident, and their associations shed light on potential impacts if researched together in future studies. Prior COR studies failed to consider a person's regulatory mode orientation. I believe that this may be an important omission, as this literature review suggests that an individual's resource situation may significantly influence their approach to goal movement and progress towards achievement (Jansen et al., 2022) and may influence resource protection and generation. Furthermore, failure to protect, create, or sustain resources may be associated with an individual's assessor or locomotor orientation. I believe that not considering an individual's locomotion and assessment orientation in COR research may lead to partial answers to the research questions.

Contextual literature review

This chapter has taken a theoretical approach to review the prior literature associated with the two conceptual frameworks. It now contextualises the theory to support understanding of the frameworks in the setting of this study.

Contextual application of the theoretical frameworks

To help explain the models of conservation of resources (COR) and assessment and locomotion contextually, two conceptual parents, Charlie and Jordan, have been created and used in the following sections. They are mothers caring for neurodivergent children and have challenging and complex lives. To set the scene, at the beginning of a new week, each mother reflects on her past, present, and future hopes and aspirations.

Charlie is from a stable and supportive family that has contributed to her career success and financial stability. Despite the challenges that her life may bring, she generally finds it manageable. She is known for her drive and determination, seeking new opportunities, and striving to improve her situation.

Jordan, our other conceptual parent, reflects on her difficult childhood in a dysfunctional

family with whom she now has little contact. Her educational qualifications were limited, she lacks family support and has few friends. Jordan struggles to make and maintain friends due to financial and time constraints and often dwells negatively on her situation. Despite this, she copes daily with little hope or plans for a better future for herself or her children. Although both parents have a neurodivergent child, their challenges and opportunities differ due to their unique past and current situations and approaches to life.

Although both parents have a neurodivergent child, their challenges and opportunities differ due to their unique past and current life situations, and approach to life.

The conservation of resources (COR) theory is a stress, resilience, and motivation theory that reinforces the importance of wider social relations and interactions (Hobfoll, 2001; Westman et al., 2004). It outlines a process for interpreting and predicting the positive and negative impacts of stressors on individuals to determine their consequent behaviour and resilience (Chen et al., 2015; Ford, 2009; Hobfoll, 2001). This theory articulates principles and corollaries (Halbesleben et al., 2014; Hobfoll, 2018) which help explain the impact of stressful circumstances and how they are likely to develop.

It is recognised in COR theory that some circumstances, specifically those that threaten or deplete personal resources, are objectively stressful, and distress and psychological stress can occur when coping options are reduced (Hobfoll, 2001). This theory suggests that individuals are naturally motivated to protect and acquire resources (Westman et al., 2004), with the loss of valued resources being disproportionately more salient than their gain (Hobfoll et al., 2018). Individuals deploy their accumulated resources to respond to

stressors and build and enhance their resource reservoirs to sustain them for future needs (Holmgreen et al., 2017).

To help describe COR processes under stressful conditions, Hart and Cooper (2001) discussed the relationship between perceived job insecurity and exhaustion. They explained that most people possess adequate resources to cope with developing stressors but may need to adopt defensive tactics by mustering additional energies and capacities from their resource reservoir as the risk of job loss and associated stressors increase. Over time, this resource use may deplete their resource base so significantly that they may experience increased stress, exhaustion, and potential burnout (De Cuyper, 2012).

Contextual application of the theoretical frameworks

Within COR, Charlie can be considered resource-rich and Jordan resource-poor.

Charlie and Jordan would be likely to recover differently from exposure to similar stressors because of their resource caravans and passageways within their social and environmental situations. Their resource positions influence their abilities to handle both anxieties and setbacks but also to seize opportunities.

It is argued in COR studies that stressful events present objective elements of threat and loss, with common appraisals held jointly by people who share a common biology and culture through which they assess and approach their lives (Chen et al., 2015). What we value most is essentially universal (Hobfoll, 2012), and includes resources such as time, mastery, well-being, harmony, safety, and a positive sense of self. The emphasis is on objective and predictable reality rather than subjective appraisal, and while individuals' perceptions inevitably play a role (Kakavand et al., 2019), in COR, objective elements prevail (Hobfoll et al., 2018).

Contextual application of the theoretical frameworks

Both Charlie and Jordan would be adversely affected if their children exhibited extreme behaviour in the supermarket when shopping. The effects of the event may affect both parents similarly, through anxiety, distress, and disrupted routines. These objective effects would be experienced by both parents, and they would deal with the effects similarly, although the parents' capacity to cope would likely vary. Charlie's more positive resource caravan may enable her to more effectively address the negative experience.

Although studies in COR theory emphasise the objectively stressful nature of an event, studies have underscored the role of cognitive appraisal and active coping when dealing with stressors. Building on a mix of control theory, self-determination theory, and COR theory Grawitch et al. (2010) reinforced the individualistic nature of personal resource allocation, proposing that there is no ideal resource apportionment either amongst individuals or within domains. Grawitch et al. (2010) examined work-life balance and people's use of resources to balance their work and home-life. The Grawitch research suggests we offset work and home-life, allocating resources on an individual basis, balancing personal choices of resource use, deciding how much of each we use, so that personal preferences influence individualised outcomes. Linked to this, the work-life balance construct considers not only potential conflict (Kelly et al., 2008) but also enrichment (Fan et al., 2021) by taking a holistic approach to apportioning personal resources across life activities.

Regulatory Mode

The two dispositions of goal pursuit within regulatory mode are assessment and locomotion. The concept of assessment encompasses the comparison, evaluation, and deliberation of goals and the potential means of effectively achieving those goals. It has been described as 'the comparative aspect of self-regulation concerned with critically evaluating entities or states, such as goals or means, concerning alternatives to judge relative quality' (Kruglanski et al., 2000, p. 794). Conversely, locomotion focuses on the initiation and sustainment of action and movement from a person's current state to a new desired state (Jansen et al., 2022).

Contextual application of the theoretical frameworks

Kruglanski et al. (2000) explained locomotion and assessment through a narrative about a driver and passenger arriving at a shopping mall. The driver parked in a space close to the mall entrance, but the passenger was frustrated because the driver did not take time to find the closest parking space. Parking quickly to achieve the goal of quick entry into the shopping centre, the driver exhibited a locomotion bias. The passenger exhibited an assessment bias by wanting the optimal parking space. Reviewing the lives of Charlie and Jordan, Charlie is idealised as a high locomotor, and Jordan, a high assessor.

In the same way that studies in COR theory identify an individual's need to continually protect, maintain, and build their resource reservoirs to protect themselves now and in the future (Kakavand et al., 2019), regulatory mode articulates individuals' need to control their present and future well-being. This may be more obvious in high locomotors who desire to progress rapidly from their current state to a desired state. However, this may also be true for high assessors with a focus on process and experience, for whom satisfaction with their present situation and optimal options for their future state are important, making moving forward possibly undesirable (Orehek et al., 2017). For high assessors, the use of valuable personal resources is more likely to focus on making the most of their current situation and experiencing what is currently available to them with less regard for the future. Notwithstanding this, time and its use are vital resources for both assessors and locomotors, and it will be considered wasted if poorly deployed (Amato et al., 2019).

Contextual application of the theoretical frameworks

Charlie's assumed higher locomotor orientation would lead to her being more organised, with greater motivation to take on and achieve goals as quickly as possible. Jordan, with an assessor bias may be more likely to carefully consider, and delay initiating goals, and those she does take-on may not be completed or may be delayed, as she is likely to prefer to make the most of what she has and can therefore exploit.

The extent to which people are sensitive to, or focus on, assessment or locomotion can also vary, as self-regulation requires both assessment and locomotion, with individuals naturally, or from time to time, having a bias towards one or the other (Orehek et al., 2017).

There are consequences of overemphasis on one orientation, which is a focus of regulatory mode research (Higgins et al., 2003).

The temporal implications of time and motion

Kruglanski et al. (2016) noted that time affects individuals as a flow and resource, and that each is distinct, but both are required for movement from one state to another to achieve goals. As a resource, time is limited, as a flow, it is boundless, but it is needed to move from the past to the future to undertake activity. Individuals value time differently (Kruglanski et al., 2016), and time considered well used by one person may be considered time squandered by another.

Lee-Yoon, (2018) established that high locomotors optimise the use of the time they have, considering it a scarce and finite resource. Lee-Yoon and Whillans, (2019) found that the more important time is for people, the more self-focused they can become, which can weaken social and prosocial behaviours, risking their well-being. There are therefore practical implications of both high locomotion and assessment orientations which can lead to negative outcomes. A high assessor focus has for example been correlated with action delays due to rumination (Kruglanski et al., 2000; Lu et al., 2021) and procrastination (Choy and Cheung, 2018; Pierro et al., 2018), as well as anxiety, depression, and low self-esteem (Litwiller et al., 2017). Outcomes such as these could limit an individual's capacity to use their resource reservoirs to achieve timely, positive use of personal resources.

The requirement in regulatory mode for individuals to invest limited time to achieve goals appears consistent with the resource investment Principle 2 of COR theory (see Figure 2-3). This principle articulates the need to expend resources to protect against resource loss, recover from losses, or to gain, or increase personal resources. Resources are likely to be used for greater effect if they are deployed efficiently and with focus. The recognition of time as a crucial resource within the regulatory mode construct may suggest that high locomotors will use resources more effectively for resource acquisition or conservation.

Contextual application of the theoretical frameworks

Relevant to Charlie and Jordan, engagement would be important through its association with mental resilience, energy, persistence in the face of challenge, sense of significance, pride, enthusiasm, and focus on life endeavours. Jordan may have fewer social networks, and less scope to exploit those she has, possibly due to having less time, or the interrelation of her social and behavioural factors.

Notwithstanding this, research by Cornwell et al. (2019) suggests that an effective balance between motivational orientations is required for effective self-regulation, and to prevent dominance of either assessment or locomotion in the process of goal pursuit if ineffectiveness and general suboptimal outcomes are to be prevented. However, this was questioned by Jansen et al. (2022), who noted no significant interaction between assessment and locomotion.

The effects of temporality have also been recognised in the cumulative effect of advantage and disadvantage for individuals, where the experience of childhood stressors, and resource advantage or disadvantage in early life is shown to influence an individual in their adult life (Voght et al., 2011). Although an event in current time is likely to initiate an individual's reaction to stress or trauma (e.g. Galea et al., 2002), background and context contribute significantly to emotional impact and reaction. Research on the World Trade Centre attack identified that context, and an individual's resource caravan passageway influenced stress outcomes and individual resiliency, where trained and experienced emergency workers were better able to deal with events and subsequent trauma than were office workers (Hobfoll, 2014).

Contextual application of the theoretical frameworks

Jordan, with her more challenged background, development, and limited opportunities, would probably have less capacity to respond to stressors and difficulties, than Charlie.

Valuing time, and its effects

All goal movement, temporal or physical, requires individuals to use or invest time resources. Higher locomotors have a natural proclivity to move forward, whereas high assessors have a preoccupation with identifying the ideal goal and means of pursuing and achieving it (Kruglanski et al., 2000; Higgins et al., 2003; Kruglanski et al., 2013). High locomotors are therefore predisposed to greater movement per unit time (Kruglanski et al., 2016). Assessors are more likely to be content with maintaining their current situation (Panno et al., 2015).

Poor time use due to restrictions, blockages, or delays is likely to be upsetting or even stressful for locomotors, suggesting the stronger locomotion orientation, the greater will be the commitment to change (Scholer and Higgins, 2012). Conversely, a stronger assessment orientation, is likely to lead to a greater need to review, compare, and evaluate, with consequent satisfaction of a current state.

Contextual application of the theoretical frameworks

Charlie and Jordan have tendencies as assessors or locomotors which can make them more, or less self-focused. This can lead to decreased social and prosocial activities, ultimately affecting well-being and happiness. Charie may value time like money, as prior literature suggests high locomotors value time as highly as money, although this may not always be the case. Jordan may have limited opportunities for creating personal time flexibility due to her more limited resource situation, contextual situation. However, for both mothers, current capacity is linked to their personal ecology, life-course and resource passageway.

Time is therefore acknowledged as an important and valuable resource within regulatory mode due to its influence on individuals' behaviours, attitudes, and emotions (Amato et al., 2019). Inevitably, time becomes increasingly important when it is perceived to be scarce, eventually becoming priceless (De Voe and Pfeffer, 2011). A study by Amato et al. (2014) examined time management behaviours and people's perceptions of their time control and found that locomotors perceived they had more effective control over their time than assessors. Amato et al. (2019) found that locomotors experience relatively greater disappointment than assessors from poor use of time investments (Amato et al., 2019).

Time is also a key resource within COR theory, and increased disappointment from poor time investment in regulatory mode may be tied to Principle 2 of the four COR principles (No.2) (see Figure 2-3). COR Principle 2 argues that people experience frustration and anxiety due to poor investment of resources. Individuals are likely to experience greater distress when the value they place on time is greater.

Time availability has practical implications, and Amsbury and Able, (2023) found that the ability to create capacity and plan life around, and through routines, is important for parents caring for children with long-term needs who experience frequent stressors and time resource constraints. Use of time management methodologies supports perceived mastery of time allocation (Macan, 1994), and achievement of objectives (Lock and Latham, 1990).

Amato et al. (2014) noted that locomotors are likely to bolster their perceived mastery by setting sub-goals and profiting from early positive satisfaction or reward from achieving these micro-goals (Mannetti et al., 2009). The converse would be that assessors may have less control over personal time and are more likely to experience less satisfaction. If assessment and locomotion can be associated with COR theory, it is likely that high locomotors will demonstrate more time management behaviours, and have more positive cognitive consequences, and stronger resource caravans and passageways.

Contextual application of the theoretical frameworks

Charlie, in comparison to Jordan, might be expected to have more freedom and capacity to organise her life through better time-management techniques, greater work flexibility, and support from family and social networks. This would help her achieve more and be more successful in goal achievement, leading to mastery, and self-efficacy, and consequently greater satisfaction, reward, perceived control.

Regulatory mode has established that creating additional personal time comes at a cost, as it must be appropriated by not doing something else, which may affect other aspects of people's lives, including their social relationships (Whillans and Dunn, 2019). Valuing time more than money should enhance subjective well-being through motivation connected to self-transcendency, and thinking beyond ourselves, leading to greater social connection (Mogilner, 2010). Conversely, valuing time like money, is associated with self-focused

values (Whillans and Dunn, 2019), which results in less social engagement. This can be linked in COR theory to condition resources (such as marriage, family life, friends, work colleagues, social support), and preservation of social bonds.

A stable predilection to prioritise time over money predicts greater social interaction, with both new and former contacts (Whillans and Dunn, 2019). Consequentially, a chronic orientation to value either time or money will influence a person's time use, and affect their subjective well-being (Whillans et al., 2016, 2017), and happiness (Whillans and Dunn, 2019)

High locomotors (cf. low), experience greater frustration and disappointment from ineffective time use or poor returns from time investments (Okada and Hoch, 2004). This may lead individuals to pursue less significant, short-term, but more achievable goals with less rewards, reducing their opportunities to tackle more significant, but less realisable goals (Wenzel et al., 2024). This may point to a link with COR theory Principles 1 and 2 (primacy of resource loss and resource investment - Figure 2-3), as higher locomotors can experience greater irritation, unhappiness, and disappointment through loss of time, and consequent poor resource investment.

Contextual application of the theoretical frameworks

It is likely that Charlie, as a locomotor, would be more driven and more able to try to achieve more, and would set more challenging goals to progress from her current situation, more quickly, compared to Jordan, the presumed assessor. Charlie, used to achieving, would likely attribute greater value to her time investments, and expect more from them than Jordan. Delays, failure, or poor goal achievement may consequently affect Charlie more than Jordan.

The evaluation of time, its effects on emotions, attitudes, behaviours, and cognitive impacts within regulatory mode, may also be linked to individuals' resource caravan passageways. People with more positive resource reservoirs and passageways may be more able to effect change and use time effectively through a greater capacity for movement, which is likely to be the case for high locomotors. This supports the finding by Amato et al. (2019) that locomotors are more likely to value their time as a quantifiable resource for enabling movement through their locomotion orientation.

Time is further linked to COR by a finding of Amato et al. (2019, p.1117) which suggests that when higher locomotors lose their time beyond repair, they experience negative feelings more than people with lower locomotion orientation. By identifying time as a key resource within regulatory mode, Amato et al. (2019) may reinforce the importance of time as a key resource in COR beyond just a time and money comparison (Zauberman and Lynch, 2005).

The likely reality is that it is a mix of personality (Kruglanski, Pierro, and Higgins, 2016) and regulatory mode (Amato et al., 2019) that ultimately determines the way individuals value time. However, it may be reasonable to assume that an individual's resource situation will have an additional influence on how they value time.

Social support as a resource and the importance of others

Social exchanges whether with strong or weak associates can support social belonging (Epley and Schroeder, 2014). The benefits of belonging and acceptance can be significant, as negative effects include misunderstanding, social exclusion, and loss of support (Baumeister and Leary, 2017; Leary, 2005). Developing social networks can offer parents perceived protected environments to share experiences with likeminded others, which supports empathy and personal comfort (Lancaster et al., 2023). However, socialising occurs at the cost of other activities such as work, study, or childcare time, (Whillans and Dunn, 2019). The longer-term effects of restricting social interaction in favour of work, or to save on time use, can risk social seclusion, disconnection, and personal sadness (Whillans and Dunn, 2019).

Personal affects resulting from an individual's regulatory mode focus are linked to their self-motivation and social situation (Carvalho et al. 2016). The risk of seclusion is associated with the quantity and quality of an individual's social connections, which can impact both psychological and physical functioning (Uchino et al., 1996). COR theory also recognises the importance of social support resources for mental health (Hobfoll, 2002; Hobfoll et al., 2012) and identifies the importance of communities for personal resilience and well-being. The value of social support by the family, friends and society, and the exchange of ideas and knowledge are noted in prior research for its perceived empowerment and improvements towards self-care (Battanta et al., 2024; Soltanian et al.,

2022). Socialising has also been identified as the happiest part of the day (Mogilner et al., 2018), where even a passing social exchange can significantly influence social belonging and fit (Sandstrom and Dunn, 2014a, 2014b).

The needs of parents caring for long-term sick children include social, practical, economic, and psychological support. Parents of diabetic children have acknowledged the need for support with educational needs to reduce their anxiety, emotional distress, and psychological stress (Khalili et al., 2025). Unmet information needs are frequently identified. Personal connections developed through social networks can help address the information gaps and aid knowledge transfer to help reduce parental frustration, helping them make more informed choices (Dalmer, 2020; Lacelle-Webster et al., 2018; Mansour, 20121; Weissheimer et al., 2020). This information work (Toms, 2019) is considered an onerous but necessary part of complex childcare routines (Laurin and Anderson, 2024).

An individual's capacity to prevent a cascade of negative events, or to recover from such, will be linked not only to their resource reservoir, but also to their resource passageways, which incorporate knowledge through education (Larasati, 2020), as well as family and community, making recovery dependent on their wider ecology, and both their past and present (Hobfoll, 2012).

Contextual application of the theoretical frameworks

It may be reasonable to expect Jordan to have a more limited, routinely challenged resource reservoir linked to her resource passageway, compared to Charlie. Charlie would therefore have a greater resource pool to draw on in the event of continued or sudden resource use through stressor experiences, leading to Jordan being less able to respond positively or effectively to additional challenges.

COR and regulatory mode and care for neurodivergent children

Parents caring for neurodivergent children are likely to find themselves practically or emotionally unable to take a break from their care obligations. The resultant stressors may affect their ability to engage effectively (Schaufelli et al., 2002). Caring for neurodivergent children may also lead to mental and physical exhaustion (Coffey, 2006), psychological distress, and potential burnout, with associated lower productivity, emotional exhaustion, and alienation from friends and others (Chen et al., 2024; Maslach and Leiter, 2008).

Research during the COVID-19 Pandemic by Jansen et al. (2022) found locomotion to be positively associated, but assessment negatively associated with positive emotions, self-esteem, optimism, and engagement. Jansen et al. (2022) also found assessment was positively, but locomotion, negatively associated with psychological distress, which may link to the desperation principle of COR theory (Figure 2-3), through the concept that "desperate people may engage in desperate actions as a coping mechanism" Jansen et al., (2022, p.11).

This contextual review will now consider negative effects of working, on parents providing care for neurodivergent children. The review will consider engagement and distress, hope, and hopelessness, before looking at the effects of contextual demands and resources on work-life balance, and literature specific to parents providing care for their children and neurodivergent children.

Prior research (Lu et al., 2021; Nohe et al. 2015) has sought to understand the extent to which work-stress interferes with the family and vice-versa. The results suggest reciprocity. Work can interfere with the family, and family can interfere with work, and both can lead to stressors, or conversely, result in bidirectional enrichment. Resources such as attitude, emotion, and behaviour (Jennings and McDougal, 2007) created in one environment have been demonstrated to improve performance in the other (Greenhaus and Powell, 2006).

Hope, and hopelessness may be common in parents caring for neurodivergent children. The concept of hope is frequently referred to in COR theory, particularly concerning resource reservoirs, caravans, and caravan passageways, in a diverse range of studies including students (Ouweneel et al., 2011), war fighting (Hobfoll et al., 2012), work-family enrichment (Hobfoll et al., 2018), and volcanic eruptions (Clissold et al., 2021).

Studies of hope in a regulatory mode by Di Santo et al. (2021) established that people with higher locomotion orientations were more likely to have hopeful thoughts and hope for the future through a positive motivational state and their effective management of their agency (i.e. motivation) and pathways (i.e. planning), resulting in greater feelings of psychological well-being and likely life-satisfaction (Bailey and Snyder, 2007). Di Santo et al., (2021) suggested that this was due to locomotors desire for and positive belief in their ability for goal-related progress. However, earlier research (Di Santo et al.2018) established

locomotion was negatively related to hopelessness, supporting Vazeou-Nieuwenhuis and Orehek. (2017) that both assessment and locomotion have indirect effects on life satisfaction through an individual's perception of purpose. Trougakos et al. (2014) considered the value of lunchbreaks at work, the outcomes of which may be applicable to this study, as employees experienced lower fatigue if they had agency over their activities during the period. Di Santo et al., (2018) confirmed the previous literature establishing that locomotion facilitates effective movement toward goals, providing encouragement and optimism, in contrast to depression and diminished well-being from poor progress (Pennebaker, 1989; Semmer and Frese, 1985).

Locomotion is positively associated with personality (Cervone, 2004). It is linked to perceived social support, optimism, self-esteem, emotion, and positive engagement, and connected to wellbeing and hope (Alarcon et al., 2011; Morris and Pinelli, 2022; Ouweneel et al., 2011). Locomotion is also linked to life and situational influences (Avnet and Higgins, 2003) such as work-life balance or social links (Cavallo et al., 2016). Understanding the extent to which individuals manage time as a resource should encompass a holistic view of both their regulatory mode (Grawitch et al., 2010), and their resource situation (Hobfoll et al., 2018). Time is a key resource, but it is just one of many within a person's ecology and the contextual factors affecting them at the time (Fan et al., 2021). These factors include the equilibrium between work-and-family which affects the quality of their parenting (Gatrell et al., 2013) through their balance of work-and-nonwork, leading to personal satisfaction or dissatisfaction with their lives (Abendroth and Den-Dulk, 2011; Valcour, 2007).

Fan et al. (2021), using a sample of working mothers with children, considered childcare time as a personal resource alongside financial situation and found that resource accumulation occurred using home-based work and established part-time work. They found the two combined to improve family and childcare time, and financial situation. Parents did not gain satisfaction from having more money, as they felt childcare quality was lost, regardless of additional income. However, it has been found that lower-income parents' gain satisfaction from investing more direct care in their children, whilst accepting reduced income (Rockwool Foundation Research Unit, 2010). Taken together, this suggests that within a resource ecology, a contextual factor may become a demand or a

resource through its accumulation or depletion impact on an individual's resources, such as a higher income having either a positive or negative impact on resources.

Continuing with context, Fan et al. (2021) using a general sample of working mothers with children, suggests working mothers work-life balance is influenced by contextual demands that lead them to exchange multiple resources, specifically finance and work hours, to achieve a satisfactory balance between finances and childcare time. Such contextual demands can be considered environmental aggravations which necessitate a response through activation of personal resources to maintain personal and family life. Fan et al. (2021) argue that an individual's simultaneous use of a range of personal resources alongside their contextual demands, will determine their work-life balance.

Fan et al. (2021) found that working longer hours, frequently working evenings, and undertaking more demanding managerial roles, had a negative indirect effect on the work-life balance satisfaction of their working mother sample. The mothers believed that they did not contribute enough time to their children's care. COR theory (Hobfoll et al., 2018) would suggest that caring for neurodivergent children is a resource demand likely to impose pressure on parents through the continual commitments to both work and family. This could lead parents to feel they have not spent sufficient time with their children, resulting in poor work-life balance (Brown et al., 2008; Kendig and Bianchi, 2008). The same research by Brown et al., found that over time, working part-time or from home, with a network of local support, facilitated resource accumulation, and improved work-life balance.

Time and money are just two key resources needed by parents to provide effective and desired childcare. But they are two resources that work in concert and are useful to demonstrate the contextual effects of personal resources and their links to time management in the regulatory mode construct. However, managing resources to ensure adequate parent-child time is a priority for all working mothers to achieve balance (Hallberg, and Klevmarken, 2003; Milkie et al., 2010), so that parents can care for their children themselves rather than arranging childcare. Parents are more likely to create the time needed by using effective time-management techniques considered within regulatory mode, and within COR through their overall resource situation.

In conclusion, research identifies that if key resources of parents caring for children become threatened with loss, are lost, or cannot be gained or regained, the parents face decreasing coping options, which can lead to psychological distress (Asbury et al., 2021, Cohn et al., 2020;). These resources can be considered objective elements of threat and loss for parents providing care for children with long-term needs as the parents share a common biology and culture through which they interpret and approach their common reality. This can be explained by the COR resource investment principle (Principle 2) which states that we invest resources to protect against loss, recover from losses, or gain resources (Hobfoll et al., 2018). With unsustainable resource loss, parents can take what may appear to be unreasonable actions, in line with COR Principle 4, the desperation principle, putting at risk or forsaking their own healthcare, well-being, and financial situation to care for their sick child. However, such selflessness can allow them to conserve their resources, giving them time to change their stressor arrays, and develop new coping strategies.

A parent with higher locomotion may have a greater drive and therefore ability, to protect or generate resources, and advance their career, which may lead to higher incomes, compared to assessor parent carers (Amato et al., 2014). A virtuous work-life balance cycle may also be supported because individuals draw on their social systems inside and outside work to augment and use personal resources to help them address stressors and create positive outcomes and augment their resource reservoirs to better cope with their work-life balance stressors (Fan et al., 2021).

Conceptual model

This study draws on COR and assessment and locomotion within regulatory mode to explore associations between the two psychological frameworks, and how they may support mothers caring for neurodivergent children. Previous research has highlighted the significance of resources and self-regulation for mothers facing challenging circumstances, including caring for children with disabilities and chronic illnesses. However, the applicability of these concepts to the parents of neurodivergent children remains unclear. The literature review for this study identified two research gaps: whether there were associations between COR and regulatory mode and the potential application of these theories to support mothers of neurodivergent children. Consequently, this study aimed to

enhance the understanding of the association between COR and regulatory mode theories and explore their relevance to mothers caring for neurodivergent children.

Drawing on this study's literature review, and gaps identified, the conceptual model presented in Figure 2.10 uses a dotted line to illustrate the potential of links or associations between an individual's COR resource situation and their regulatory mode orientation of assessment and locomotion. In the literature review, potentially significant internal and external resources for individuals were also identified. Personal internal resources include an individual's resource situation and regulatory mode orientation as shown at the top of the model. Shown below these are resource passageways, resource gain or loss situations, mindfulness, current stressors, and personal knowledge and abilities. Four potentially significant external resource factors are also shown in the model. These are the condition and behaviour of neurodivergent children, institutional support (challenges and assistance), work/family/social support and pressure, and the health and psychological support of parents.

Previous research has identified both internal and external resources as crucial for mothers facing challenging circumstances, including caring for children with disabilities and chronic illnesses. These resources may also be pertinent to mothers of neurodivergent children. Each personal internal resource and external resource factor is depicted in the model as potentially impacting and influencing the parents of neurodivergent children, as illustrated by the blue and magenta arrows. The magenta arrows emphasise the importance of individuals' COR resource situations and regulatory mode orientation. The potential impacts and effects are represented by the blue central blocks. The initial effects begin with the generation of positive or negative impacts on parents. This may lead to anxiety, stress, or eustress. Parents' responses will be linked to their current personal situations. Their responses affect their ability to manage stressors by protecting, maintaining, replenishing, or creating resources. The outcome of this process is the development and maintenance of parental resilience and coping capacities.

To add detail to each of the internal and external resource factors, I draw on the literature review. Turning first to an individual's resource situation, this underlines the significance of various resources including time, social support, financial resources, self-efficacy, self-esteem, self-control, self-confidence, optimism, mastery, and hope. Regulatory mode

orientation, specifically assessment and locomotion, influences individuals' behaviours, affecting their time utilisation, time management, task and goal focus, change focus, and tendencies towards urgency or procrastination. Resource passageways encompass the effects of an individual's past experiences, personal ecology, and social and environmental conditions, all of which collectively contribute to cumulative advantages or disadvantages. The resource gain or loss situation reflects an individual's current situational resource gain or loss situation, which impacts resource protection, investment, and acquisition. Mindfulness encompasses emotional regulation, consideration for oneself and others, satisfaction, well-being, and contentment. The impact of stressors is evaluated in terms of individual levels of anxiety, distress, and stress. Personal knowledge and abilities pertain to the parents' capacity to act effectively for themselves and their children.

The conceptual model identifies four external resource factors. First, the significance of neurodiversity and children's conditions and behaviours encompasses the parents' physical and psychological states and their consequent effects on parental stress and capacity. Challenges and help related to institutional support encompass the impact on parents arising from processes, procedures, and interactions with schools, local authorities, and healthcare professionals. Pressures from work-family and social support include cultural belonging, practical assistance, knowledge support, and the positive and negative crossover of resources alongside the broaden-and-build concept. Finally, parental health and psychological support includes counselling, medication, therapies, and both psychological and physical support and training.

The applicability and influence of these personal internal and external resource factors on mothers caring for neurodivergent children will be explored through the findings of this study. Research findings will also explore possible links between the two psychological frameworks.

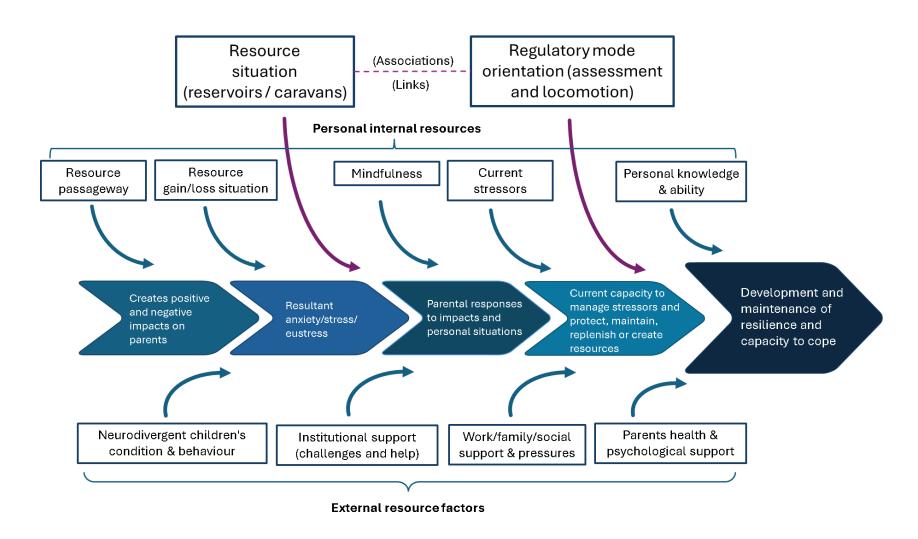


Figure 2-10: Conceptual model of the connections between locomotion and assessment, and conservation of resources for mothers caring for neurodivergent children (author devised)

Conclusion

This chapter has reviewed relevant literature on parents caring for neurodivergent, and chronically sick children and the effects of childcare on the parents. It has also looked at COR theory and regulatory mode to consider how and why individuals approach stressors, relationships, life challenges, personal progress, and goal pursuit. The literature is reviewed theoretically, and contextually to support meaning and understanding. The chapter considers mechanisms that translate individual, social, organisational, and societal factors into behaviours and outcomes, and why outcomes will differ from one person to another.

This literature review specifically considers time and social support as key resources in both theoretical frameworks. The influence of an individual's past and the extent to which it determines their current and future ability to cope with stressors and the likelihood of future success are explored. The concept and relevance of resource caravans, caravan passageways, and an individual's wider ecology have been reviewed. As the aim of this study was to develop practical interventions for mothers caring for neurodivergent children to support their resilience and enhance their coping capacity, this chapter has also focused on the literature surrounding parents providing long-term care for their children.

The gaps in the literature that have been identified relate to whether there are associations between the two theoretical constructs and whether the two constructs may apply to mothers caring for neurodivergent children. A more nuanced understanding of the relationships between COR and regulatory modes may shed light on the direction of relationships within both constructs, an issue routinely referenced within research in both theories.

A conceptual model is presented in Figure 2-10 which illustrates the potential of connections between COR and regulatory mode orientations, and possible personal internal resources and external resource factors that may affect mothers.

3 Methodology and methods

Chapter 2 reviewed relevant literature on parents caring for children with long-term needs, the theoretical, and contextual application of the theory of conservation of resources (COR), and constructs of assessment and locomotion within regulatory mode. A conceptual model developed from the literature review is set out, showing how COR and regulatory modes appear to be associated. Aspects of the two conceptual models were explored, with a focus on time, resource caravan passageways, people's time management behaviours, their personal resource situations, and the role of social support.

After reiterating the aims, objectives, and research questions, this chapter begins by discussing the philosophical foundations used, and methodological design. It briefly addresses the alternative qualitative design options considered. The chapter reflects on the role of the researcher, covers ethical approval, and outlines the research process. It goes on to discuss the recruitment of the study sample, considers the pilot studies, and explains the interview and transcription approach, followed by data collection, management, and data analysis. Reflexivity is reviewed as a factor contributing to trustworthiness and transparency of the research process, along with other approaches, to support rigor to demonstrate the overall suitability of the methodology.

Aims, objectives, and research questions

Providing long-term care for demanding children can be challenging, often leading to recurrent stressors that affect parents' ability to cope, general motivation, well-being, and overall sense of hope.

This study aims to address the gaps in literature identified during the literature review: the associations between COR and regulatory mode, and the potential application of these theories in supporting mothers who care for neurodivergent children. In addressing these gaps, the study seeks to develop practical approaches to strengthen the resilience and coping mechanisms of mothers caring for their neurodivergent children, using the psychological frameworks of conservation of resources (COR) theory and regulatory mode. Five objectives were established to achieve this, which led to five research questions, which are set out in Figure 3-1. The research aimed to answer these research

questions considering the two psychological frameworks of COR theory, and the self-regulatory orientations of assessment and locomotion of regulatory mode.

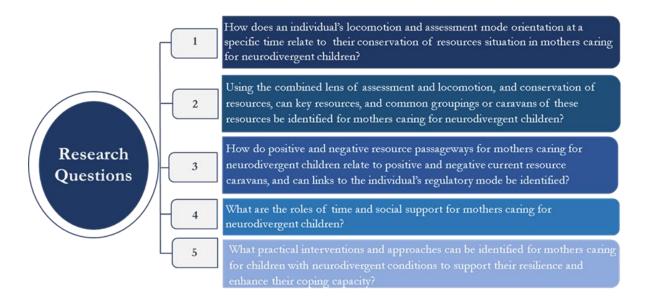


Figure 3-1: Research Questions (author devised)

Research approach

Most previous studies within COR theory, and regulatory mode have employed a quantitative approach, developing extensive empirical data (e.g., Kruglanski et al., 2000; Schaufeli et al., 2002; Bonanno et al., 2007; Orehek et al., 2017; Howard, 2019; Fan and Potocnik, 2021; Lu et al., 2021; Sprung & Rogers, 2021; Muhlenheimeier et al., 2022; Jansen et al., 2022). Within both frameworks, fewer, but valuable qualitative research data has also contributed depth, and useful experiential understanding (e.g., Hobfoll et al., 2012; Zee and Kumashiro, 2019; Clissold et al., 2021).

This study aims to understand the experiences of parents caring for neurodivergent children, who are individuals living particularly challenging, time-pressed lives (Cohn et al., 2020; Asbury et al., 2021). Greater understanding will help determine whether the day-to-day experiences of these parents' links specific aspects of COR (Hobfoll, 2001) and regulatory mode through their assessment or locomotion orientation (e.g., Amato et al., 2014).

Eisting literature is scarce on how parents caring for neurodiverse children consider, deal with, and address their life stressors through the two studied constructs. To develop insight into the perceived realities of stressed, time-pressed parents caring for neurodivergent children, and the psychological and physical factors affecting them, a qualitative methodology was adopted. Other research methods were considered, but as the positions of the study's research philosophy, ontology, and epistemology solidified, it became clear that it was the researchers understanding and interpretation of the thoughts and perceptions of the individuals that would be of overriding importance. This was unlikely to be achieved through scales and instruments.

Qualitative research encompasses various approaches, but it is essentially 'a set of complex interpretive practices without a single discipline that studies subjects in their natural settings to make them visible to the world' (Denzin and Lincoln, 2018, p. 43). Qualitative research helps reveal meanings behind a phenomenon, not the cause and effect of the connection (Merriam & Tisdell, 2015, p.5), with a focus on identifying and understanding the ways individuals perceive their experiences, associating meaning to them (Merriam & Tisdell, 2015). The output from this approach supports the creation of detailed representations of participants' characteristics, behaviours, thoughts, and values that may otherwise go unnoticed or remain unclear (Creswell and Creswell, 2017; Cruz and Tantia, 2017). As such, a qualitative methodology supports the investigation of human conditions while employing a methodological approach for data processing and interpretation for theory development (Cruz and Tantia, 2017).

Study background

This study develops practical interventions to enhance parental resilience and coping mechanisms to support parents caring for neurodivergent children through greater understanding of the conceptual models of COR, and assessment and locomotion. The idea for this study developed from a general interest in the extent to which the empirical data generated in quantitative COR studies adequately understood what participants were considering, experiencing, and feeling when they responded to questionnaires. Empirical results lead researchers to interpret rather than understand the reasons behind results. This study was subsequently nuanced by asking whether what appeared to be a previously unlinked, but possibly associated construct of assessment and locomotion within

regulatory mode may be influenced by an individual's resource situation, and conversely, whether an individual's COR situation may be influenced by their regulatory mode. Using these two theoretical models, this study initially sought to develop proposals to support parents providing long-term care for sick children.

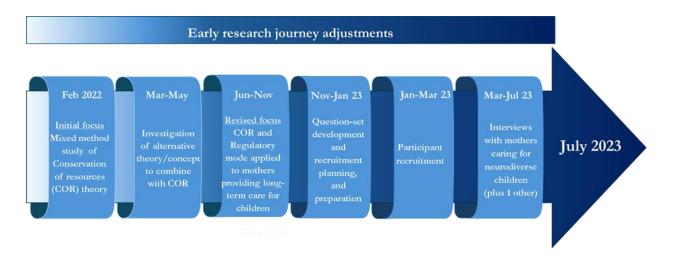
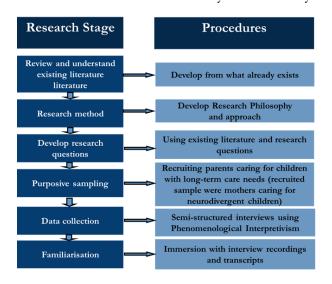


Figure 3-2: Illustrative summary of early adjustments during this study's research journey (author devised)

Notwithstanding the research intention, the recruited sample transpired to be mothers caring for neurodivergent children, and these mothers became a central phenomenon of the study. They were people about whom the researcher had only limited, preconceived assumptions regarding the practical and experiential challenges they encountered in their day-to-day lives. A table summarising the early research process is in Table 3.1.

Table 3.1: Illustrative summary of this study's early research process (author devised)



Trustworthiness

Trustworthiness is a critical component in qualitative research, as it upholds ethical responsibility, ensures integrity, and fosters credible, reliable, and meaningful findings. Qualitative research entails the examination of complex social phenomena, human experiences, and perspectives. Establishing trustworthiness enables readers to ascertain that the research accurately represents participants' views and is methodologically sound. By implementing appropriate procedures, qualitative researchers can enhance the trustworthiness of their studies, thereby demonstrating the robustness of the findings, their credibility, and their potential applicability to broader contexts. Table 2 summarises how the researcher has addressed the criteria for trustworthiness in this study.

Table 2: Table showing trustworthiness criterion for this study (author devised)

Trustworthiness	How it was addressed in the research		
criterion	How it was addressed in the research		
Dependability	Audit trails – maintained records of research processes and decisions made		
(consistency and	during data collection, analysis, and interpretation.		
reliability of the	Code-recode reliability approach – coded, then recoded the same data to		
research process,	see if the codes remained consistent after a time gap.		
related to reliability)	Peer review/audit – other researchers frequently reviewed the		
	methodology, data analysis, and findings to check process reliability.		
	Reflexivity – continuous reflexion on researcher function, possible bias, and		
	influences.		
Credibility	Triangulation – data were collected in NVivo and Excel and extensively		
(truth, believability and	compared during the analysis. Other academics were asked to review the data		
accuracy of the	and methods. Routine reviews of current news on neurodivergent issues,		
findings)	both locally and nationally.		
	Prolonged engagement – interviews were long and open, in part, to		
	develop effective relationships and trust, and enhance understanding.		
	The peer debriefing-research process and findings were routinely		
	discussed with colleagues to consider alternative perspectives.		
	Reflexivity – continual awareness and acknowledgement of potential		
	researcher and participant biases - assessing potential impact on research.		
	Rich descriptions – contextual, detailed accounts of the data–supported the		
	understanding of the findings.		
	Purposeful sampling – describing sampling methods and characteristics of		
	the sample supported judgment of whether findings could be transferred to		
	other circumstances.		
	Member checking – This was purposefully not done, as the author		
	considered it could introduce participant bias.		
Confirmability	Audit Trail – the research process was carefully documented; data		
(objectivity of the	collection, analysis, interpretation, to demonstrate that findings came from		
research and findings,	the data. The data structure is shown in Appendix X.		
to ensure they are	Reflexivity – potential researcher and participant bias and possible		
based on/shaped by	influences on the research are recognised and discussed.		
the data rather than	Peer Review – reviewed by external researchers to verify the findings		
any researcher bias)	emanated from the data and not researcher bias.		

	Triangulation – used multiple data sources, cross-referenced, to limit bias.		
	Bracketing – set aside as far as possible researcher preconceptions, allowing		
	the data to speak.		
Transferability	Contextualisation – this research was conducted with mothers caring for		
(extent to which the	neurodivergent children, often with more than one child being		
findings can be applied	neurodivergent, sometimes one child had more than one divergence, and		
to other populations or	frequently, siblings had different neurodiversity's. Findings, therefore, apply		
settings)	generally to mothers and likely to parents of neurodivergent children. They		
	may also apply in large part to parents caring for children with long-term		
	illness.		
	Thick Description - granular explanations of research participants context,		
	and settings. Allows readers to decide whether the findings are applicable to		
	other groups or contexts.		
	Use of Purposive Sampling – the sample used represents varied		
	experiences within what became the target population, allowing greater		
	generalisability.		

Research Philosophy, Ontology and Epistemology

This study adopts the research philosophy of phenomenological interpretivism and undertakes a deep exploration of the participants experiences in their cultural and social contexts. The philosophical foundations of phenomenological interpretivism are closely bound to the wider makeup of interpretivism in the discovery of knowledge (Ferdiansyah et al., 2022). Interpretivism stresses the subjective nature of knowledge and values the way that individuals interpret and attribute meanings within their own unique contexts (Miettinen, 2017). This approach is rooted in the notion that all human actions are meaningful (Garrick, 1999). An interpretive approach was considered appropriate for determining the human experiences perceived by parents caring for neurodivergent children, the participants of this study.

Table 3.3: Summary of research philosophy, approach, and rationale (author devised)

Philosophical stance and approach	Approach used	Rationale
Research Philosophy (or philosophical approach)	Phenomenological Interpretivism	Phenomenological interpretivism focuses on the analysis and description of phenomena. At the core of phenomenology is the way things appear to the person or people experiencing the phenomena. There is an emphasis on removing researcher bias and prejudice to gain deeper understanding of participants' experiences. The interpretivist perspective seeks to understand the essence and significance of the human experiences as it is perceived by those involved.
Ontology (The nature of being or reality)	Subjectivist	A subjectivist view considers reality to be subjective, evolving from the perception and experience of the individual. It argues that there can be no objective reality independent of our mind.
Epistemology (What constitutes reality)	Interpretivist	Interpretivists think knowledge is constructed and created through interpretation. It is argued there is no true, single interpretation of reality, but there are multiple interpretations, shaped by the individual's perspective and context.
Research Methodology	Qualitative	Qualitative methods are used to collect data about participants' experiences and their interpretations of those experiences.
Research approach	Inductive	Assumptions are developed from observation, with untested conclusions.
Time horizon	Cross-sectional	A snap-shot study in which the phenomena is studied once.
Practice	Humanistic	The study adopts a humanistic approach.
Axiology (The role of values)	Value-laden and biased	Value bound, with the researcher integral to the research and inseparable, subjective.
Research Methods	Qualitative mono- method semi- structured in- depth qualitative interviews	The interpretivist perspective aims to understand the human experiences perceived by those experiencing it. The researcher is interested in understanding the phenomenon from the voices of the participants.

The focus of phenomenology is understanding and interpreting the lived experiences and perceptions of individuals' (Smith et al., 2009). Discussing theoretical approaches to phenomenology and social constructivism, Dempster and Hanna (2015) identified phenomenology as the belief that the experiences of others can be determined through research concentrating on their experiences and perceptions. While the researcher is epistemologically drawn toward a social constructivist perspective of reality constructed through interactions with others, greater comfort is gained from the belief that our independence as individuals is paramount and that it is the lived experiences that are truly dominant, rather than a social construction of reality. This led to an interpretivist epistemology.

The phenomenological discipline requires a first-person approach through the exploration of individual's awareness, observations, and understanding, since it considers the individual's experience as theirs alone (Crotty, 1998). Phenomenology requires us to not look at things as they are, but to suspend our developed comprehension, and create a new understanding of the phenomena in a specific context, to see what becomes apparent for us through re-interpretation, since 'phenomenology is a reflective enterprise, and in its reflection, it is critical' (Larrabee, 1990, p. 201).

A phenomenological approach encourages researchers to 'set aside their previous habits and thoughts, to learn to see what stands before our eyes' (Husserl, 1931. P. 43). For this study, this means discounting as effectively as possible any current interpretations or assumptions about how the mothers may be affected or impacted by their neurodiverse children's behaviours. The researcher must as far as possible start afresh and consider the experiences of the participants anew, creating the capacity to develop new meaning through revised and enhanced interpretations (Crotty, 1996).

This study focuses on developing an analysis of meaning within the phenomena revealed through the words and descriptions (Rasid et al., 2021) of mothers providing care for their neurodivergent children. One approach to this putting aside, is the use of bracketing or epoché which is an important part of the process of phenomenology, through which we lay aside our understanding to look afresh at what is before us, to better understand the experiences of the participants (Moustakas, 1994).

The essence of phenomenology is the "collection and analysis of people's perceptions related to a specific, definable phenomenon" (Dawidowicz, 2016, p.203), and in its design and process, phenomenology takes an inductive approach with themes derived from the collected media (Saunders et al., 2019); interviews in the case of this study. This approach allows the researcher to develop patterns and categories to organise and analyse statements from which meaningful units of data can be identified, grouped, and arranged as themes (Lewis, 2015). Through phenomenology, this study tries to understand what parents providing care for neurodivergent children experience, their realities, and inductively derived lived experiences (Merriam and Tisdell, 2015).

Ontology and Epistemology

The integration of a subjectivist ontology and interpretivist epistemology used in this study takes note of the diversity of subjective experiences and the importance of understanding the social and cultural perspectives in which these experiences occur. This philosophical framework is particularly relevant in qualitative research paradigms, where exploring individual perspectives and meanings is at the heart of knowledge-making.

A subjectivist ontology argues that reality is created through an individual's experience and perception. This ontological approach encourages a relatively varied and comprehensive strategy of knowledge generation, reinforcing the subjective nature of reality and rejecting the notion of a single independent reality (Bunniss and Kelly, 2010). The perspective suggests that knowledge is dependent on the interpretations and experiences we have as individuals, and on what we understand, and is derived from reflection rather than just lived experiences (Ormston et al., 2014). This ontology supports a more thorough investigation of different perspectives and experiences. Edwards et al. (2021) highlight the potential advantages of such an ontology for gaining insights into, and dealing with, complex healthcare challenges, which aligns with the subjectivist view of the importance of individual experiences and the contextual factors that shape them. It is the way that individuals interpret and understand what they experience that is important to the construction of knowledge (Al-Saadi, 2014), although Peter and Park (2018) argue that there is a need to reflect on both subjective and objective realities in research.

The interpretivist epistemology adopted in this study emphasises the importance of understanding individuals' interpretations, and the meanings they create within the contexts that they are experiencing. Taking an interpretivist approach supports the development of a rich yield of contextualised insights vital for developing an understanding of the complex dimensions of the social phenomena under investigation (Black, 2006). This epistemological stance also emphasises the role of social context, language, and communication in the process of interpretation (Adcock, 2003; Chowdhury, 2014), as the interpretivist approach acknowledges the importance of recognising the role of others' perspectives when researching the meanings underlying our understanding of human behaviour, connections, and personal society (Pulla and Carter, 2018).

Research Methodology

The qualitative research methodology used in this study incorporates a distinct but developing array of approaches embedded in several disciplines (Siddiqui et al., 2021). As a methodology, qualitative research is routinely deployed in fields such as social sciences and health, where the lens is focused on studying and interpreting experiences, attitudes, behaviour, and beliefs and it is often used to safeguard the appropriateness of interventions, principally in the context of health and illness (Meissner, 2011).

A qualitative research design embraces several conventions of qualitative research (Lewis, 2015), and the methodology emphasises subjective consideration, with the subjective focus judged to be a positive quality (Arizavi and Choubsaz, 2021). Qualitative research is acknowledged for its thoroughness, and the quality of the research approach is a prominent factor (Mays and Pope 1995). This methodology requires the collection and analysis of non-numerical data using methods such as interviews to obtain insights into the experiences, perspectives, and meanings of individuals or groups. In doing so, it focuses on context, understanding, and the complex subjective nature of the research focus.

Alternative methodologies, specifically, the use of a narrative approach, and case studies. were considered. Narrative Inquiry focusses on collecting complete sequenced stories from a few participants. The approach is common in healthcare and psychology and is a valuable method for establishing and reviewing qualitative research (Sandelowski, 1991) as it supports detailed and descriptive analysis to inquire about how people construct the meanings of life experiences (Rosairo, 2023). However, as this study required statements

from a broad spectrum of participants to address several specific research questions, it was considered that a limited number of sequenced accounts detailing a flow of related events (Saunders et al., 2019) was not the most appropriate method for this study.

A case study approach, which involves the examination of an individual, group, or other unit over time to develop an understanding through the triangulation of data from multiple sources (Creswell and Creswell, 2017; Schoch, 2020), was also considered but excluded. A case study design which typically involves a limited number of participants, could prevent the discovery of the variety of lived experiences envisaged as being essential for this study. The need to gain insights into the experiences and challenges encountered daily by a diverse group of individuals who would be participants in this study was paramount.

The inductive approach of this study, utilising qualitative data, provided fresh perspectives and was particularly valuable for developing a deep understanding of the phenomenon and generating new theoretical insights. The humanistic approach adopted accentuates the intrinsic value of individuals, and their virtues (Friedman, 2008). It is an approach commonly used in qualitative research as it allows researchers to collect and conduct a thorough analysis of detailed information about individuals' experiences to develop a deeper understanding (Lewis, 2015). It helps reveal the meanings and values that individuals attribute to their reality, perceptions, and experiences (Özden and Tuncay 2018). By acknowledging the importance of human values, this approach also considers the ethical and moral implications of this study.

Axiology

Axiology considers the role of values in research (Saunders et al., 2009). This study is value-laden, and this applies to both the researcher and the participants, who are biased by their life course, experiences, culture, and knowledge (Al-Ababneh, 2020). Inevitably, these factors influenced this research.

The function of the researcher

The researcher will inevitably have predispositions and preconceptions before the research journey begins and will develop new ones during the research; researcher self-awareness throughout the stages of the research activities is necessary to avoid subjectivity and bias (Ravitch & Carl, 2019). This awareness includes the extent to which the researcher can

influence data collection and interpretation (Silverman, 2020), as well as their influence on participants through their reactions and responses when engaging with them (Dawidowicz, 2016).

In this study, the researcher's situation is summarised as a parent with two neurotypical children. The researcher has not been closely associated with anyone who has been in a similar situation to the participants and is only able to note and interpret rather than truly understand or validate the emotional or physical effects that providing care for a neurodivergent child can have. As a parent, the researcher has experienced concerns about their own children's injuries, distress, health, and welfare, but such experiences have been relatively inconsequential, and transitory. The researcher therefore had neither experience nor previous knowledge of the experiences of the study participants, their experiences regarding their children, or how they interpret or contemplate the future.

Aside from acknowledging awareness and embracing the principle of bracketing or epoché to put aside preconceived ideas during data collection and analysis, the researcher took steps to continuously undertake self-assessment to both understand and be aware of any bias they already had or developed during the study that could impact data collection and interpretation. This was achieved by maintaining a general awareness, but also by maintaining a reflexive journal.

A reflexive journal can improve researcher self-awareness, helping them understand how they interpret data and construct knowledge from it (Finlay, 2002). Acknowledging thoughts and feelings regarding the qualitative research process can also create an additional valuable source of data to enhance the thoroughness of the ethical and methodological approach (Smith, 1999). Maintaining a personal record of reflexions during data collection is important not only for gathering thoughts and feelings, but also for offering the researcher the opportunity to learn from the research process (Thorpe, 2010). This is important, as data interpretation can be significantly affected by researcher subjectivity and bias towards the research area (Alvesson and Sköldberg, 2009; Ravitch and Carl, 2016). Such a bias may occur, for example, if the researcher experiences mental discomfort, which may open the possibility that the value or even the truth derived from the data collected by the researcher could be threatened (Chenail, 2011).

Ethics approval

Ethical approval was granted by the Research and Ethics Committee of Liverpool John Moores University. UREC Minimal Risk Registration Number - 22/LBR/008 was authorised following the Minimal Ethical Risk Guiding Principles for this study-

The issue of participant and child anonymity was important in this study, and potential participants were reassured of this in the participant information and consent documentation (see Appendices A and B) and in the interview preamble. Participant names and details and all transcripts and recordings were kept in the university One-Drive secure storage. Pseudonyms were used for the participants' children and husbands/partners.

Research design and methods

Having explained the research philosophy and approach, the next section describes the research method and conduct of this study. Subsections take a sequential method, detailing the approach to interviews, sampling, criteria for participant inclusion, and participant recruitment. The chapter discusses the participants, the interviews and their adjustment, data collection, transcription, and data analysis.

Using a qualitative approach to data collection, interviews were used to understand the participants' perceptions and experiences. The interviews were semi-structured in-depth qualitative interviews, which provided a degree of control over the process (Bryman and Bell, 2015). Questions were used that allowed and encouraged follow-on researcher-guided conversation as well as unguided participant input. The aim was to generate a deep understanding and awareness of the participants' thoughts, motivations, and beliefs to appreciate their perspectives and experiences (Charmaz, 2014). This approach supported understanding of the studied phenomenon (Patton, 1990; Gall et al. 1996). The interviews were cross-sectional and snapshots.

The researcher expected participants to be stressed, time-constrained, and challenged. To help deal with this, Holloway and Jefferson (2013) recommend adopting a counsellor relationship between researchers and participants with a focus on listening, reflection, and feedback to acknowledge participants' experiences. This approach was adopted in this study. It was evident that detailed preparation was important, as care would be needed in

all dealings with potential and active participants. The pre-contact process and interview routines were made as easy and efficient as possible.

The opening preamble for interviews was carefully considered, as the pre-discussion would set the tone for the interview relationship. Thought was given to how to approach questions that could be perceived as intrusive, and how to respond if participants became upset during the interviews. The length and content of questions were tailored to keep them succinct but effective, and interview guide drafts were trialled and adjusted until an acceptable product existed. Ultimately a friendly but professional approach was developed to support responses that would provide rich and valuable data.

Participant recruitment

Purposeful sampling was used in this study. This method supports the selection of suitable participants and helps ensure sufficient appropriate participants for interview to attain data saturation (Patton, 2015), which was the point at which new data ceased to uncover additional information (Korstjens and Moser, 2018). Purposive and strategic sampling is often used for qualitative research, as it can help a researcher actively focus on a specific population, allowing a greater understanding of how that population experiences a phenomenon (Ravitch and Carl, 2019).

It was originally planned to focus on single parents caring for chronically sick children under the age of 18 who were unable to use mainstream education. The reason for this sample group was that it would best meet the study's focus on resource caravans and resource caravan passageways alongside goal achievement through locomotion and assessment. However, early discussions with parents and childcare specialists as well as prior literature on parents caring for sick children led to a revised selection criterion. Effectively defining a chronically sick child and reconciling it with potential participants was also difficult, as was defining a single parent in modern relationships, although helpful guidance can be found in Merriam-Webster (2021). Participants in the considered cohort may have children at a mix of special and mainstream schools. Some parents have children at home because the children are unable to cope at school or may be withdrawn or excluded from the school for various reasons.

After reconsideration, it was decided that what was needed was parents who provided long-term care for children and were continually dealing with stressors, were time-constrained, and routinely made decisions that were challenging, specifically regarding their own life and relating to the children they cared for. Despite these considerations, as has been stated, the recruited sample were all mothers caring for neurodivergent children.

Participant selection aimed to identify parents who would be relevant, reliable, and likely to provide the data needed (Morse, 2007). The participant demographics recorded in Appendix D, and the children's demographics are in Appendix C. These demonstrate the homogeneity of the sample for subsequent cross-case reviews (Smith et al., 2009).

Recruiting participants can be challenging (Donovan et al. 2014; Perez, 2022). The target sample for this study were potentially stressed, time challenged parents, and the need to discuss what could be sensitive issues was likely to discourage people from applying to take part. The requirement for online video interviews could have also discouraged people who may prefer anonymity, as video interviews can be perceived as little different from face-to-face interviews (Ellard-Gray et al. 2015). The length of the interview was also a possible detractor for participants, for whom an interview of over an hour would almost certainly consume valuable time and may have been a salient consideration (Perez, 2022). Early establishment of an appropriate positive and open initial relationship between the researcher and interviewee was important, and the researcher was mindful that care would be needed in all communications with potential and actual participants. These factors were important practically, but so too, were the ethics surrounding the need to respect potentially vulnerable participants by not wasting their time or abusing their commitment to the study (Mac-Seing et al. 2021).

Participant recruitment for this study was ultimately a journey that presented more dead ends than openings. The researcher envisaged identifying and working with a gatekeeper to help recruit participants (Namageyo-Funa et al. 2014), and early discussions in November 2022 with a hospital consultant who treated the children of many suitable parents led to hope that this would be possible. Unfortunately, the consultant became unavailable and the colleague who took over her work failed to respond to emails. Other potential gatekeepers similarly failed to develop any participant leads or ceased responding to emails.

Between mid-November 2022 and the end of April 2023, 20 special needs schools with children who met the criteria were reached-out-to, as well as local and national charities for children with severe disabilities, chronic, or terminal illness. Several local authority special educational needs and disability services were also approached. Few responses were received, but of the few who did respond, two said they would promote this study in their newsletters, and the other said they were unable to help. Approximately 90 approaches to organisations were made by phone and email during the participant recruitment journey.

Although the recruitment journey was frustrating, it was understandable because many of the individuals it was hoped could be recruited were likely to have particularly challenging lives with significant time constraints. It was reasonable to expect that few of them would be motivated to give-up limited time to a study about which they would have little understanding. Potential gatekeepers would also be busy, aware of the significant difficulties faced by the parents, and sensitive to the lives those parents led. The gatekeepers would reasonably be loath to add to their own pressures, or the burden of potential participants.

Recruitment progressed once the researcher opened a Facebook account and joined or tried to join parental support groups associated with children who needed long-term care. Applications were made to join 57 relevant appropriate groups. Admission was granted, or the site agreed to post on the researcher's behalf, on 25 of the sites. In several cases Facebook sites refused membership, but the administrative staff agreed to post a flyer. Support was also provided by two special education needs (SEN) charities who promoted the study to their members. Potential participants were mostly identified through direct responses to the flyers posted on Facebook groups or through two SEN charities. A second poster promotion was accepted on a few Facebook sites approximately six weeks after the first flyer was posted, yielding an additional five expressions of interest. A copy of a flyer is in Appendix E.

Contacts with potential participants through Facebook occurred between 5 April and 1 June 2023. Although the flyer provided an email address and QR code to contact the researcher, most responses were via the Facebook direct messaging facility. Following the exchange of email addresses, potential participants provided basic details of their children and personal circumstances for the researcher to review their fit with the selection criteria.

Potential participants meeting the criteria were sent information sheets and consent forms via personal email, the conditions to which they agreed by returning the email containing the consent form and a clear statement of their acceptance and agreement.

Copies of the participant information sheet and the electronic consent forms are in Appendix A and B. Participant information was kept clear, non-academic, and brief. It was drafted and revised to provide a succinct, simple explanation of the research concept and what would be expected of participants, along with assurances regarding confidentiality, the future use of their data, and the risks and benefits of their involvement.

If the electronic consent and participant information were not agreed to, the recruitment process ended. Of 29 expressions of interest, nine did not progress to interview. Potential participants slow to respond were chased by email up to three times. Three of the 20 interviewees were generated through a snowball effect following interviews with other participants. Participants accepted into the study were contacted to advise them of their inclusion and a mutually agreed time and date was set for interview, with a Teams invitation sent by the researcher.

Recruitment relied on parents putting themselves forward, and subsequently, study criteria fit. The resultant sample was a cohort of mothers who were generally well-educated, and caring for neurodiverse children, and one mother caring for two children with Type 1 diabetes whose data was not subsequently used. All interviewees were encouraged to pass on the details of the research to other potential participants, particularly fathers, although no male participants volunteered.

During the recruitment journey a reflexive diary was completed to record the researcher's thoughts and progress in linking with potential participants. This recorded the challenges of the recruitment process but also recorded the researcher's feelings and emotional journey during participant recruitment. Having looked at several simple diary applications, Journaley was identified as an ideal platform for this purpose (screenshot in Figure 3-3).

The determinant for participant numbers was established through advice and research, particularly the principle of thematic saturation (Saunders and Townsend, 2016). The literature on how many participants is appropriate varies, but Saunders and Townsend (2016) advise that qualitative interview studies should use between 15 and 60 participants.

A similar range was suggested in a review of 560 qualitative PhD studies by Mason (2010), who identified the most common sample size in the range of 15 to 50 participants. However, a range of factors, such as the methods adopted, their application, and the scope of the study are also relevant (Baker and Edwards, 2012). The reality is that the researcher should cease conducting interviews when it is evident that no additional data are generated, and this judgement is the responsibility of the researcher.

For this study, it was apparent after coding the 16th interview transcript, that additional interviews were reinforcing what had already been coded and that thematic saturation had been reached. Despite this, further interviews, transcriptions, and coding were carried out to ensure that thematic saturation had indeed been reached, but also to generate additional data to reinforce and enhance the analysis for questions (RQ) 1-3. RQ 1 examines how an individual's regulatory-mode proclivity relates to their COR situation, and RQ 2 considers resource caravans and their groupings. RQ 3 investigated links between resource passageways, resource caravans, and regulatory mode.

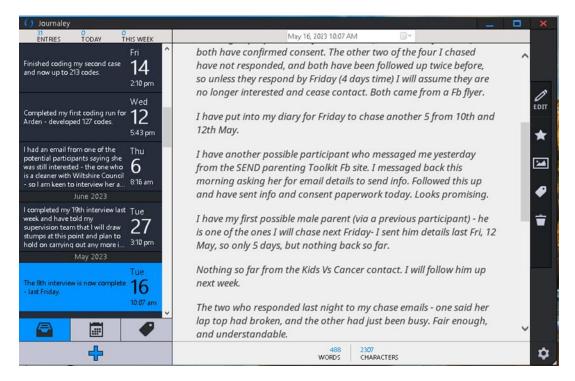


Figure 3-3: Screenshot of the Journaley platform used as a reflexive diary

The participants

Demographic data were collected for each participant. Developing and presenting demographic data in qualitative studies is valuable if it supports a more comprehensive understanding of the research context. Incorporating participant demographics can support the identification of similarities, patterns, or differences within the study population, helping contextualise the findings and support understanding of how different demographic factors may influence the phenomena under investigation (Lewis, 2015; Gustafsson et al., 2021). Demographic data can also enhance the transferability of qualitative research findings by providing insights into how the results may be applied to other settings or populations (Hannes et al., 2015). The inclusion of demographic data also aligns with the notion of research transparency and accountability, contributing to the overall trustworthiness of the study (Morrow, 2005).

The contra argument to presenting demographic data in qualitative studies focuses on the possible emphasis of bias and limitations of categorisation. The complexity of human experiences may be lost by incorporating demographic variables, thereby introducing the potential for oversimplification. In this respect, it may be argued that this could be at variance with a qualitative approach. The need to acknowledge and be aware of the implications and potential drawbacks of presenting demographic data in qualitative studies is important (Baker et al., 2023).

The final sample consisted of 19 mothers who cared for children whose age ranged from four to 22 years. All children were neurodivergent and several had comorbidities. Some had suffered health conditions and disorders aside from their neurodiversity since birth, but others had developed or established them post-birth. All but one of the participants lived in the United Kingdom, one having relocated abroad a few years previously. Demographic data are in Appendices C and D.

The nineteen female participants were aged 32–57 years and had an average age of 45 years. In all cases, the mother was the main caregiver and decision-maker for the children. Eighteen of the 19 participants worked. Three were employed full-time. Eight were employed part-time, seven were self-employed or freelanced part-time. Part-time working hours ranged from a few hours to 30 hours per week. Children being cared for ranged in

age from eight to 22 years, and the number of children with neurodivergent conditions in the family ranged from one to five. Two mothers cared for children with mobility restrictions due to paraplegia or cerebral palsy. Several children had numerous and often significant co-morbidities.

Interviews

Semi-structured interviews were used as the primary data collection tool, and all pilot or participant interviews were conducted online using Microsoft Teams and recorded through the Microsoft Teams voice and transcription facility. The content and structure of the interview guide drew on Kvale's 9 types of interview questions (Kvale, 1994), employing for example, introductory statements, follow-up, probing, direct and indirect questions, and silence. Questions within the interview guide were grouped into five data segments addressing stressors, support, life course, time value, and time management (see Figure 3-4).

Pilot interviews (see chronology in Figure 3-6) tested the participant paperwork and initial drafts of the interview guide to capture how both were interpreted, and the general flow of the questions. Following adjustments, a trial of the overall process and the revised interview guide was conducted prior to initiating the participant interviews (Chenail, 2011). Following revisions, clearer paperwork, and an effective interview guide were developed. This provided questions that could be followed closely but flexibly, rather than rigidly (Rubin and Rubin, 2011). The interview guide with its prompts ensured the researcher's focus remained consistent (Holloway and Jefferson, 2013) whilst allowing flexibility to develop useful avenues of participant-initiated discussion and comment. This approach limited deviation from the research focus while ensuring the freedom to explore and reduce potential insensitivity towards participants that might occur by taking an approach which was less structured (Chenail, 2011; Dawidowicz, 2016).



Figure 3-4: Illustrative summary of the interview guide groupings (author devised)

The researcher was conscious of their own possible impact on participants who may be anxious, stressed, and would almost certainly have more important things to do with the hour or more they would commit to the interview. During planning, consideration was given to quickly developing and maintaining a connection and affinity with the study participants, encouraging openness (Polit and Beck, 2009), and encouraging and developing trust and acceptance, which is key to qualitative data collection (Creswell, 2006; Marshall and Rossman, 2015; Parahoo, 2006).

An initial pilot interview to review the process and interview guide was conducted in January 2023 with four participants. None of the pilot interviewees fitted the research selection criteria; their purpose was to review and provide feedback as educated outsiders on the sensitivity of the process and draft questions and their scope to generate appropriate responses. Pilot interview 1 and subsequently, pilot interview 2, assessed the practicability of the research design by addressing the objectives set out in Figure 3-5, which also identifies proposed outcomes. The pilot and subsequent participant interviews are discussed in the following sections.

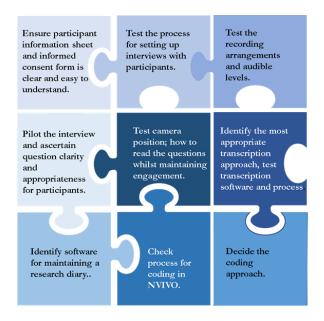


Figure 3-5: Illustrative summary of the pilot study objectives set by the researcher (author devised)

Although there is little reported research concentrating on how pilot studies should be conducted (Malmqvist et al., 2019), pilot interviews are acknowledged as an important preliminary step in developing an effective interview process and guide (Majid et al., 2017), not least for semi-structured interviews (Malmqvist et al., 2019).

Pilot 1 participants were sent the patient information and consent forms. These participants were initially asked to provide feedback on the structure and content of the revised participant paperwork. Feedback led to additional adjustments to simplify and shorten the wording to make the information sheet more understandable. In addition, a section was added to clarify the selection criteria. The gatekeeper information was also adjusted to make it clearer.

The initial interview guide was tested subsequently with three new pilot participants. Changes were made to the questions, and some questions that may have been challenging for stressed people were refined (Sampson, 2004). Other adjustments made the questions clearer and more defined, for example a question that asked about the participants weaknesses, was changed to ask about the main negative aspects of the participants life now, with a follow-on question to ask what had contributed to that. A question asking how the participant looked at the future, was adjusted to ask for thoughts about the future,

and what gave the participant hope. Some significant changes from Pilot 1 are shown in Appendix F. Pseudonyms are used in the pilot interview extracts.

In addition to an initial review of the proposed questions, a focus of Pilot 1 was how best to read the questions while focusing on the participant and maintaining eye contact, as it was too easy to be seen looking at prompts or jotting notes. It also became clear during the first pilot interview that the researcher needed explicit cues for the pre-interview briefing and post-interview debriefing to ensure a coherent and succinct introduction. It became evident during the Pilot 1 interviews that it was not just the questions that were important, but the whole approach taken with the participants. This reinforced earlier thoughts that simple things like building empathy and maintaining eye contact to make the interviewee the focus of the interview, whilst creating an impression of informality, were important (Aung et al., 2021).

A revised preamble was developed using a listening style (Lavee and Itzhakov, 2023). This aimed to settle the participants and quickly establish a relationship, whilst also discovering additional information about them, such as where they were located and whether their children were with them. Ethical and consent requirements were confirmed and agreed during the preamble, as was recording of the interview. The aims of the study and the interview and its content were outlined, and principles such as pausing or ending the interview, were covered. The preamble advised participants that the interview would be as informal and relaxed as possible and would focus on what the participant felt and thought. Finally, the preamble made it clear that the interview was about the participant and not the child or children, while clarifying that there were initial questions to understand some details about the children's conditions. Post-interview points were also reviewed during pilot interviews. These included checks that the interview had not adversely affected the participant and asked if participants if they were content to be contacted again if needed.

Pilot 2 interviews provided additional feedback on the interview guide. One of the interviews was with a professional counsellor, and the other participant had a child who had been and continued to be affected by Long Covid. Much of the focus of Pilot 2 concerned the identification of questions that could have potential to cause distress. The need for the researcher to be alert to the possibility of upset was established during the development of the interview guide.

The need for awareness was confirmed by a concern by the interviewee about a relatively innocent question asking whether they were alone, or with their children, which had aimed to establish detail regarding the family situation. It was felt that this could cause interviewees to worry that the researcher, a male interviewer, could be establishing whether the participant was routinely alone at home, creating a potential threat for the future. This question was adjusted to ask who was at home with the participant at the time, with prompts of where the child or children were and whether there was a partner, etc., to support the participant and/or whether they sometimes have help at home.

A generic question asking the participant to provide details about their childhood and youth, was broken down into a series of questions which included "looking back over your life, what would you say were the key events for you, starting with your childhood?" And "are the memories you have generally positive or negative?" Another question which asked how much the participant felt in control, was adjusted to "to what extent do you feel you can take control of your time and manage it, how do you feel you do that?" A question that asked the participant about their thoughts for the future was amended to ask two questions, firstly "what do you think the future holds for you?" And "do you think your past life has influenced your outlook on the future?" Extracts from pilot 2 interviews are in appendix H.

Several questions were supported by prompts that helped gather additional data and allowed participants to articulate their experiences more fully through greater reflection (Mishler, 1991). An example of this was a question to develop data on participants regulatory mode, which asked "think about setting yourself a goal, or having something to achieve, which is most important to you, perfection and accuracy, or speed and achievement", with a prompt "why is that do you think"? Although the final guide remained firmly in the format of a semi-structured interview, elements had evolved to incorporate a vaguely narrative interview feel by allowing participants to express their understanding of events and experiences (Mishler, 1991) and providing opportunities for them to expand on subjects they found relevant and important (Thomas et al. 2014). This also provided an opportunity to obtain additional data during coding.

The final interview guide comprised a valuable set of questions developed and refined from the original conceptual draft. During the pilot interviews, several potentially challenging and unclear or confusing questions were revised or removed. The final interview guide supported and encouraged participants' open expressions to elicit rich data for subsequent analysis.

Data collection and management

Interviews with participants were conducted between March and July 2023. Figure 3-6

Month	Instruments	Outcomes	Remarks
January & February 2023	Pilot 1 interviews.	Conducted pilot interviews on 4 individuals of different ages and family situations.	Revised preliminary paperwork, introductory comments, and several proposed questions
March 2023	Pilot 2 interviews.	Reviewed interview questions.	Reduced the number of additional questions and organised questions more clearly by grouping within subject areas.
March to July 2023	Participant interviews.	Conducted 21 interviews with 19 mothers who provided long-term care for their children.	Two interviews were split to fit with the participant requests to allow them time to meet their care needs their neurodiverse children. Further adjustments were made to the interview guide following the initial interviews, and the final iteration of the interview guide was effective from the fifth participant.

shows the schedule. All but two participants completed the interview in one session. The other two interviews were carried out in two parts at the request of the participants, who needed to break up the interviews to accommodate their children's routines. For this reason, 22 interviews were conducted with 20 participants, although the interviews of only the 19 mothers caring for neurodivergent children was analysed.

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Figure 3-6: Illustrative summary of the chronology of the interview process for the pilot and main interviews (author devised)

The semi-structured interviews with the study participants were conducted online. Online meetings were adopted because of the likely physical distances involved, because it would take up the least time, and removed the need for participants to travel, park, or walk to a meeting location. Logging into an MS Teams meeting was simple, quick, and incorporated a degree of safety for both the researcher and the participants. It was an approach endorsed and encouraged by the supervisor team.

The pre-interview script helped create a relaxed interview environment and relationship between the interviewer and interviewee. From the start of each interview, short notes of any relevant observations to support subsequent data analysis were jotted in an interview book to support analysis (Saunders et al., 2019).

The final interview guide (see Appendix G) proved to be effective in supporting the collection of valuable data for analysis, and the development of rich information to address the research questions (Merriman and Tisdell, 2015). As planned, the interview guide helped the researcher steer the discussion and consequently, the participants, while also providing flexibility to explore any significant discussion areas more deeply as they developed.

Participants were watched carefully during their interviews for signs of distress. Although a few participants experienced upset at some points, most were consistently cheerful and upbeat. When participants appeared distressed, they were asked if they were happy to continue, and in all cases, they were. Community-based support network links had previously been provided to participants on the recruitment information literature. Occasionally, during the interviews, statements provided by participants were conflicting, and the accuracy or even truthfulness was doubted, but ultimately, what was said was taken at face value. As Holloway and Jefferson (2013) suggest, we cannot know better than the participants whose lives we are studying.

The average duration of the interviews was approximately 1h 30 minutes, with a range of 1h 10 minutes to 2h 10 minutes. The audio recording was saved as a Word document, and the video was saved as an MP4 file. Pseudonyms were given to each participant when the files were exported to the University One-Drive secure storage to preserve anonymity.

The research process was qualitative (Collis and Hussey, 2013) and followed an inductive approach through interpretivism (Jankowicz, 2000) supporting the phenomenological interpretivism research philosophy set out in Table 3.3. The interview questions generated open and frank responses from the participants, which led to a wealth of rich data, which was analysed and used to answer the research questions.

Interview transcription

Following each interview the MS Teams generated transcripts were reviewed as soon as possible by watching and comparing the transcription with the video recordings. This provided familiarity and an initial evaluation of what had been said. It identified any issues about the interview process and highlighted key points that had arisen during the discussion while allowing an initial immersion (Saunders et al., 2019) in what the participants had said

and how they had expressed themselves. The corrected transcripts were not shared with participants for their comments, as interviewee transcript reviews by participants have been shown to add little and can detract from providing what was said during an interview (Hagens et al., 2009).

Although commercially available transcription packages were trialled, the auto-generated transcriptions from MS Teams proved to be effective and could subsequently be corrected using a split screen showing the auto-transcript from MS Teams, and video recording. The video recording could be paused with a mouse click while the transcript was corrected, and the recording could then be restarted to compare the next section with the written transcript. This approach was not too time-consuming and, importantly, supported a deeper understanding of the context of the participants' comments within the overall discussion.

Minimal transcribing conventions were used to remind the researcher of the feel of the interview. Simple transcription conventions were appropriate for the research purpose (Crang, 2005) and provided a subsequent reminder of the tone and feel of the discussion at that point in the interview (Kvale and Brinkmann, 2007). The focus was to record how the participants communicated their feelings and thoughts rather than their behaviours or actions, endorsing the minimal use of conventions (Bazeley, 2013).

Corrections were made to the transcripts. These were needed to ensure that the participants' comments could be better understood during subsequent coding. The initial transcripts could be misleading and even provide an incorrect record of what had been said. However, keeping the transcribed interview close to what was said supported a more flexible approach to data analysis whilst also helping the researcher immerse themselves in the qualitative data (Neal et al., 2015). Adjustments and corrections to the initial transcripts helped acquaint the researcher with the data prior to initial coding and data extraction. Transcript adjustments were made as soon as possible to help maintain familiarity with the nuances of the discussion. Handwritten notes made during the discussions further supported accuracy (Crawford and Lyn, 2016).

Coding and theme development

As the original data is purposefully fragmented, a system for data management and retrieval and subsequent regrouping in its new formatting, along with other data of similar meanings and interpretations is needed (Saunders et al., 2019). This was achieved in this study through the coding process, by which data from the interviews were identified using a code or concept summarising the meaning of the extracted data, codifying it for further analysis.

Both NVivo and Excel were used for the data analysis and code or concept development in this study, predominately because the researcher envisaged the range and complexity of the data needed to answer the research questions might be too extensive to record only in NVivo. Although data from both applications would be used to address all the research questions, it was expected that Excel would be mainly used to develop information to support research questions on participants' resources and regulatory mode orientations, and NVivo would be used to gather data to answer the other research questions. As the data collection from the transcripts progressed, it transpired that the planned recording differentiation between the two applications was not so distinct, and analysis for all research questions drew on both applications.

Thematic analysis is a specific method rather than a methodological approach and is commonly used in qualitative research (Braun and Clarke, 2006). It is not theoretically bound (Joffe and Yardley, 2004), and perhaps because of this, and its flexible approach, there are no rigid procedures for its use (Tuckett, 2005). This study made flexible use of the method described by Braun and Clarke (2006), utilising their reflexive thematic analysis approach for the theme development in NVivo, and adopting their more thematic analysis, using a more codebook approach for the code or concept and theme development in Excel. An outline of the process used following Braun and Clarke is summarised in Figure 3-7.

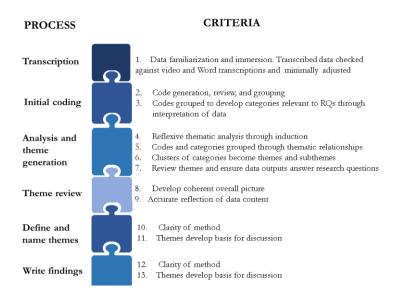


Figure 3-7: Coding and theme development and generation (following Braun and Clarke, 2006)

Excel provided the advantage of developing a more visible record of the statements as it was collected, allowing the emerging data to be more easily visualised than was the case with NVivo. As planned, the Excel workbook recorded demographic data on the study participants, and data was collected under categories relating to their stress, and hope, to capture each participant's resource situation or caravan, and information relating to their assessment and locomotion proclivity, resource passageway, and data relating to how participants viewed and valued time and managed it. Figure 3-13 shows the final headers and codes or concepts developed through each participants Excel spreadsheet.

This study also drew on Gioia et al. (2010, 2013) work to develop the data structure. An interpretive approach supported the identification of first order concepts rather than codes, second order themes, and aggregate dimensions (Gioia et al., 2013). The term concept rather than codes will be used going forward to reflect the Gioia terminology.

The next sections describe the data collection, first in NVivo, and then in Excel.

Corrected transcripts were imported into NVivo to create a file, with each file representing a participant. The first interviewee was Arden, and her named transcript became the first file. Files were coded as soon as time allowed. The first concept group was labelled 'initial concepts', and preliminary concepts were developed by working through the imported transcript files. The nature of the process resulted in the ascribed codes being routinely reviewed.

The range of concepts within the initial concept group developed quickly, with concept entries (Silverman, 2020) reflecting the essence of the statements made by the participants. An extract of the initial inductive concepts is in Figure 3-8, with examples which included 'can be difficult to plan the day', 'carers can add to stress', and "carers provide practical support". During coding of the initial transcripts, it was necessary to review previously coded files in a 'concurrent and recursive fashion' (Saunders et al., 2019, p. 652) as first order concepts developed, which helped to ensure consistency of coding and analysis.

a. Initial co	des	Q S	Search Project			
Nar	me				Files	Referen
O Cor	nmunity is importa	ant			2	2
O Cor	norbitities				1	1
O Cor	ncern for others				3	3
O Cor	nstant grind of care	is a n	egative		1	1
O Cor	nstant grind of care	is neg	gative		2	2
O Cor	nsultancy gives job	flexibi	ility		2	2
O Cou	uncil poor perform	ance ir	ncreases wor	rkload	1	1
O Day	starts around 6 ar	m			2	2
O Day	starts at 6.30-6.45	am			1	1
O Day	s are long and har	d worl	k		2	4
O Dea	aling with meltdow	ns afte	er school		1	1
O Dea	aling with one issue	atat	ime		1	1
O Dea	aling with what you	ı can, s	small steps		1	1
O Dea	ath of parent(s) sign	nifican	it event		1	1
O Dis	abled brother signi	ficant	in her life		1	1
O Dis	abled child is what	itis			1	1
O Dis	abled sibling influe	nced l	ife choices		1	1

Figure 3-8: Sample of initial concepts from NVivo.

The first interview transcript, which was coded in early July 2023, resulted in 127 concepts. The second transcript added an additional 86 concepts, the third transcript produced 66 more first order concepts. After coding the fourth transcript there were 350 concepts. The coding of the second transcript resulted in only 9.8% of the concepts having more

than one file or transcript linked to a concept, indicating that a similar comment had been made by at least one other participant. By the fourth transcript, 25% of the concepts had more than one file associated with a concept. This established that the concepts were gradually standardising, or the phenomenon was re-occurring, demonstrating the strength of opinion towards it (Saunders et al., 2019).

It became practically difficult to use 350 concepts, and in late July 2023, an extensive first-pass review of extant concepts was undertaken to develop concept categories, combining similar or repeated concepts and child, or sub-concepts under parent concepts.

An example of an initial first order concept grouping was combining 'need for downtime', 'not used to relaxing', and 'parental wellbeing is missed'. These were combined to create 'need for personal time'. The number of concepts was reduced to a manageable set of 75 concepts and categories incorporating several nested child concepts grouped through thematic relationships. This second coding iteration was labelled 'reviewed initial concepts' and these became the base line for subsequent coding. A screenshot of several of the final reviewed initial concepts in early September 2023 is in Figure 3-9.



Figure 3-9: Extract of the reviewed initial concepts from NVivo.

Examples of concept reduction and combining for this iteration were bringing together 'constant demands and challenges are stressful', 'challenges, demands and responsibility is stressful', and challenging behaviours are emotionally draining', all of which were put under the concept category of 'neurodiverse care is demanding and time consuming'. The concepts evolved into more generic summaries of people's experiences, or central concepts encapsulating the meaning of similar contents. Examples of generic concepts include 'close family support as a variable', 'disparate approach to children', and 'institutional support not always helpful or supportive'. The concepts also incorporated sub concepts, an example of which is the parent concept of 'disparate approach to children', with two sub concepts of 'sick child is a dominant focus', and 'the other child doesn't get a look in'.

The developing concepts were reviewed again to create the 'revised concept' (pre-theme) set, prior to identifying second order themes (Gioia et al., 2010, 2013). This review refined the concepts by removing several new duplicate concepts and combining similar ones that had been developed over the previous month of coding. The number of concepts was reduced to 71, much the same number that followed the previous concept review. Theme development was conducted in line with the Braun and Clarke (2006) methodology, but any nascent themes that had emerged during transcript analysis when interesting data were noted. The thinking behind those conceptualisations had been recorded in the research diary for subsequent use (Silverman, 2020) during theme development.

The essence of thematic analysis is the search for relationships and patterns within the data, progressing to the identification of collective data or themes for further analysis to answer research questions (Saunders et al., 2019). Themes summarise content or a conceptualisation of a central concept. A theme may be a single concept but will usually incorporate numerous related concepts; and will represent a concept that is considered important to the research questions. Coding organises the raw data, theme development groups the previously coded data to create categories for analysis.

The researcher was keen as far as possible to not allow preconceived presumptions to influence theme development, and to ensure that themes were the product of what was said by the participants. This was in part achieved by being thorough, but also by an early active engagement with the videos and transcripts to reveal and develop data from what

had at times been very personal discussions with the participants. Such precoding of early activities can be critical for data analysis (Layder 1998).

Data structure

The final first order concepts, second order codes, and themes, are shown in Table 4. This summarises and clarifies the development of the data to establish themes and aggregate dimensions (Gioia et al. 2010, 2013). Table 4 is Table 4: Data structure shown again without the links to the RQs in Appendix W but also includes examples of representative quotes underlying the first order concepts.

Table 4: Data structure based on Gioia et al. (2010, 2013)

1 st Order concepts	2 nd Order themes	Aggregate Dimensions	Used to address research question(s) Main contribution(s) bold	
Local authority support [is] unhelpful and				
stressful	Negative effects from	External factors	4, 5	
Limited practical support stressful	institutional support	External factors	4, 3	
School support poor and stressful				
Mainstream school attendance				
Child being home educated	Children's schooling	External factors	4,5	
Education concerns				
Social media support, advice and information	Social media	External factors	4 , 5	
Social media unhelpful	Social media	External factors	4 , 3	
Family support variability				
Sibling support variability				
Social support - emotional & psychological				
Social support – negatives	Commont	External factors	4 5	
Social support - practical advice	Support		4 , 5	
Social support - practical help				
Social support - reassurance & friendship				
Social support in the workplace				
Parental wellbeing is needed	Personal wellbeing	Personal factors	4, 5	
Carers parents can have positive impact	<u> </u>			
Personal attributes	Positive factors		4 5	
Situational factors	Positive factors	Personal factors	4, 5	
Support factors		Personal factors		
Additional costs for neurodiverse children	Additional aballances		4 5	
Neurodivergent parentage	Additional challenges		4, 5	

Challenges, demands and responsibility is stressful Children's issues can be complex Days are long and hard work Employer not always helpful or supportive Mother on medications and therapy Neurodiverse care is challenging, emotional and exhausting Presumptions of neurodiversity School holiday challenges Time is limited			
ND child focus [the] Other child takes second place	Child focus	Child focus	4, 5
Time is limited, so needs controlled use Need time for mental wellbeing ND care can be time consuming Time management techniques Need more time Limited time limits activity Professionals can waste time Short-term approach	Time		4, 5
Positive or negative approach Upbeat or down Sensitivity, supportive and sympathetic Energy starting the day Ability to deal with complexities	Ability to deal with stressors	Resource situation	1, 2, 3, 5
Hope for the future What gives hope?	Evidence of hope		1, 3,5
Goal achievement approach Energy	Assessor or locomotor orientation	Regulatory mode orientation	1, 2, 3 , 5

Driver or passenger				
Controller or controlled				
Multitasking evidence				
Short-term or long-term approach				
Attitude to time-use				
Procrastination proclivity				
Approach to evaluation of self, or others				
Past life positives and negatives				
Influencers and influences				
Positive/negative view of past life				
Changes to past life		Empowering, opening,		
Positives now	Resource passageway	limiting, or restricting	1 , 2, 3 , 5	
Negatives now		passageway		
The future				
Influence of the past on current life				
Future hope				
Time or money orientation				
Options for creating more time				
Use of spare time	Mental approach to time	Value placed on time	1 , 2, 4 , 5	
Use of additional money				
Use of additional time				
Relaxation activity approach	Time management	Assessor or locomotor approach	1 , 2, 4 , 5	
Use of time available	Assessment or locomotion			
Control and management of own time	characteristics	Time management	1 , 2, 4 , 5	
Activities organisation	CHATACICHSUCS			

The themes, subthemes, child-themes, and their aggregates, developed from the analysed data are presented in a thematic map in

Figure 3-10. A key is shown under

Figure 3-10 to explain the organisation of the themes within their aggregate dimensions (Gioia et al., 2010).

Figure 3-10 shows the four aggregate dimensions highlighted in red, green, brown. Themes making up each aggregate dimension are shown in circles. Subthemes are shown linked with each theme, and where appropriate, associated child-level themes are also shown.

The aggregate of 'external factors' encapsulated in red, shows four themes of social support, social media, schooling, and institutional support. Each theme has links to subthemes which are shown in capitals. The theme of 'social media' within the aggregate of external factors for example, has two subthemes: social media can be unhelpful, and social media provides support, advice, and information. Encapsulated in green the aggregate of personal factors shows themes of personal wellbeing, additional challenges, and positive factors. The subtheme of 'positive factors' has eleven child-themes, which include ability to self-advocate, acceptance of situation, and flexible approach. Child focus, with a brown surround, has one sub theme. Time, surrounded with a blue line, has eight subthemes, with the subtheme time management techniques having four child-themes.

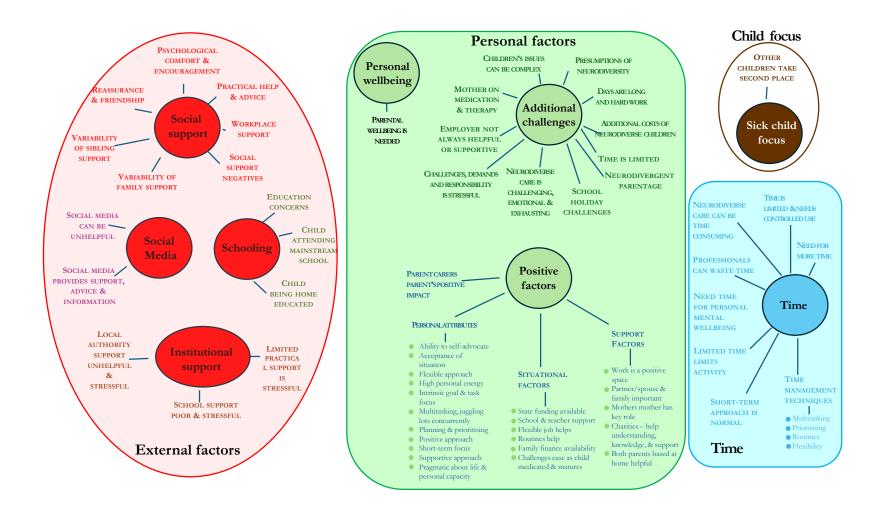


Figure 3-10: Thematic map of themes for mothers providing care for neurodiverse children.

KEY: Red section aggregates external factor themes and sub themes. Green section aggregates personal factor themes, sub themes, and child themes – e.g. 'support factors' is sub theme of positive factors, and 'work is a positive space' is a child theme of support factors. Brown surround shows child focus theme and sub theme. The blue surrounded grouping is the time theme, with sub themes, and child theme for time management techniques.

Eight themes were developed using NVivo which identified factors that significantly influenced the mothers in their daily lives. The additional theme of time was developed using data from both NVivo and Excel. All nine themes are shown on the thematic map in

Figure 3-10.

To help understand the aggregate dimensions (Gioia et al., 2010) of the themes developed using NVivo, I developed the summary in Figure 3-11. The themes are shown in the three aggregates of: personal factors, external factors, and neurodivergent child focus. The theme of time included in the full thematic map in

Figure 3-10 is not shown in Figure 3-11. The three personal factor themes, coloured green, are the mother's (personal) well-being, negative effects from the additional challenges they face, and constructive effects from positive factors. The external factor themes coloured red, are the negative effects of institutional support agencies, support from within and outside the family, social media, and children's schooling. A neurodivergent children focus, coloured brown, stands alone as a theme. These coloured aggregates in Figure 3-11 reflect the coloured aggregates in Figure 3-11.



Figure 3-11: Summary of the eight key themes developed using NVivo, for mothers caring for neurodivergent children – source: the author

The theme of social support in

Figure 3-10 specifically addresses RQ 4, which considers the role of social support in both the theoretical models considered in this study. The other themes provide data to address RQ 5, identifying interventions to support parents caring for neurodivergent children.

RQ 4 also considers the significance of time for parents caring for neurodivergent children. Data relating to time to address RQ4 was specifically collected and analysed in both NVivo and Excel to develop first order concepts and second order themes (Gio et al., 2013). The resulting concepts were refined through a separate first and second-pass processes to develop the time themes. This was to maintain their integrity. Data collected in Excel to support the determination of the participants' assessment and locomotion orientations also provided information on the significance of time for the participants. These results were compared with other relevant data recorded in Excel to further verify the conclusions (Saunders et al., 2019). Figure 3-12, identifies eight-time sub-themes. Excel was also used for further analysis to explore whether additional information could be developed from the data.



Figure 3-12: Theme of time for research question 4, extracted from

Figure 3-10. Key – subthemes within time are shown in capitals. Child-themes for time management techniques are shown in lowercase

Concept and Theme development in Excel

As the concepts were developed using NVivo software, statements were also copied and pasted into Excel spreadsheets for each participant under a few initial broad headings which were expanded spontaneously to capture data relating to participants under broad headings of stress, hope, regulatory mode, resource passageways, time management, and the way participants valued time. The concepts under these broad headers on the spreadsheet for the first participant developed much as the concepts evolved in NVivo, as statements from each transcript were identified, and pasted into the spreadsheet. The evolving spreadsheets for each of the initial participants formed the basis for the next participant spreadsheet. The nature of the process resulted in the ascribed codes being routinely reviewed. As the concepts developed during coding of the first four participants' transcripts, the previous participants' spreadsheets were changed to incorporate the new concepts, and the previous transcripts were reviewed. By the 4th transcript, the spreadsheets, and coding schema required only minor adjustments. However, the data to answer RQ 2, which identified the key resources for participants, took all 19 transcripts to evolve, with the final nine key resources not finalised until the last transcript had been coded.

Figure 3-13 shows the concepts developed in Excel to identify statements that could address RQs 1, 2, 3, and 4. The spreadsheet was set-up with headers for stress and hope to capture data concerning the individuals COR (resource) situation, assessment and locomotion for regulatory mode orientations, resource passageways for the participants life-course, and time value and management to record data on the importance and use of time. Transcript data developed the subcategories under each heading.

The resource situation of each mother was assessed based on data regarding their capacity to manage stressors and their level of hope. Individuals use resources to protect and recover from resource losses; those with stronger reservoirs are better equipped for stressors. Ability to deal with stressors explored mothers' stress and anxiety, particularly regarding supporting children, life events, and control over life now and in the future. These factors are linked to how resource loss affects individuals' feelings about achieving

basic needs, future goals, and progress. Hope was the second factor considered to investigate participants' resource situations. Recent COR studies highlight hope as a resource for mitigating stress and enhancing engagement while promoting psychological well-being. Hope, linked to optimism and motivation, is a critical force for recovery from significant stressful events.

Stress and Hop	oe .								
Positive or negative approach	Upbeat or down	Sensitivity, supportive and sympathetic	Energy starting the day	Can deal with complexities	Evidence of stress	Overall perception of stress & burnout	Stress level	Норе	What gives hope?
Assessment ar	nd Locomotio	n							
Goal Achievement	Energy	Driver or passenger	Controller or controlled	Multitasking	Short-term or long-term approach	Poor time use attitude	Pro crastination	Evaluator - self & others	
Resource Pass	sageway								
Past life	Influentcers	Positive or negative view of past	Changes to past life?	Positives now?	Negatives now?	The future	Influence of the past	Future hope	
Time value									
Time or money	Options for more time	Spare time use	Additional money use	Additional time use					
Time manage:	Time management								
Relaxation activities	Use of available time	Control & management of own time?	Activity organisation?	Assessment or locomotion characteristics					

Figure 3-13: Summary of the concepts developed in Excel (author devised)

As examples, in Figure 3-13 the stress and hope header generated subcategories which included 'positive or negative approach', 'upbeat or down', and 'can deal with complexities. An example of data contributing to the stress and hope subcategory development was the following quote, which identified the need for the subcategory of positive or negative approach.

T've learned you have to cope with the ups and downs of life because life's not linear, it's full of ups and downs and there's gonna be good times and there's gonna be s**t times and it's a case of rolling with the punches' (Ocean).

The above example suggested a positive approach, and a more positive resource situation. Conversely, the following quote suggested a more negative approach and less positive resource situation.

"The other day, when I was in therapy, I mentioned that I just wanted to drive into a tree. It's not that I want to kill myself, it's just I just want a break, because if I was in hospital, I wouldn't have to do all this every day' (Luxor).

The preponderance of relevant statements led to the addition of other subcategory's, such as sensitivity, supportive and sympathetic'. The following statement for example, suggested a more positive approach, with negative stress, and a more positive resource situation.

'I try my best to support all the parents as well who are in a similar situation as me. (Kingsley). Conversely, a statement by Kit identified reduced capacity for sensitivity, support or sympathy, suggesting a less positive resource situation.

"...outside my family I lose patience with people really. I just mainly keep myself away from others" (Kit).

Subcategories developed quickly, and the substructure became clear after the first 4 or 5 transcripts. Previous transcripts were revisited to reassess them for data on the new subcategories, once the structure was established.

To further demonstrate the data used to capture stress and hope, and assessment and locomotion, comments of one of one participant's relating to their stressors, and assessment and locomotion orientation, are shown in Appendix I. This shows data indicative of an assessment orientation highlighted in blue font and the examples of locomotion in red font. The data suggests attention to detail and accuracy rather than rapid goal achievement, suggesting an assessment orientation, as assessors tend towards accuracy (Mauro et al., 2009).

Each element of the data was assessed and often compared and re-compared to numerous cells in the spreadsheet to review one set of coded data against another, as well as evidence from the NVivo concepts, and often, from revisiting the literature review.

In addition, prior literature had been analysed using NVivo to identify characteristics of assessment and locomotion orientations. This provided a useful reference to support the determination of each mother's regulatory mode (see extract examples in Appendix J).

In the same way that some data was recorded under more than one concept in NVivo, some was recorded in both NVivo and Excel and often more than once in the Excel spreadsheets when it had relevant contributions to make.

Once the spreadsheet for each participant had been completed, and stress and hope to assess the participants' resource caravan had been made, their resource passageway, time valuation, and time management data entries were reviewed to check if the assessments appeared correct and were congruous under each header (i.e., did the determination of stress and hope align with the resource passageway determination, and did a determination of a locomotion orientation under assessment and locomotion, correspond to the determination under time use). This process started with the final coded participant, since the accuracy was felt to be more refined by the nineteenth transcript than it had been at the start of the coding. Several adjustments to earlier assessments were made, indicating that the exercise was both worthwhile and necessary.

Excel spreadsheet data became the focus for research questions 1, 2, and 3 (see Figure 1-1). RQ 1 asked how participants assessment and locomotion orientation at a specific time relates to their conservation of resources situation. RQ 3 considered whether positive and negative resource passageways correspond to positive and negative resource caravans, and whether links to regulatory modes could be identified. The data for RQ 1 and 3 was assessed by creating a new spreadsheet populated from the existing Excel data to show summary assessments of each participant's stress, hope, resource caravan, assessment, locomotion orientation, resource passageway, time valuation, and time management – see example in Figure 3-14. Each assessment summary was red, amber, green (RAG) colour coded to help identify and compare the resource level assessments for each participant more easily. Red indicates an inadequate level of the resource, amber an intermediate level, and green an adequate level. The full spreadsheet is provided in Appendix K.

The first row beneath the headers in Figure 3-14 shows the summarised assessments for one participant who demonstrated negative stress and positive hope, which suggested an adequate resource caravan. Statements made by them also suggested they had a locomotor dominance, and a positive resource passageway. They valued having additional time over additional money, and their approach to time management suggested a locomotor orientation. The latter confirmed the assessment and locomotion summary assessment.

In contrast, the participant summarised in the third row of data of the summary in Figure 3-14 indicated positive stress and negative hope, suggesting they had an inadequate resource caravan, and they had an assessor dominance, and a challenged resource passageway. The participant placed greater value on having additional time over money, and their approach to time management suggested an assessor orientation. Appendix K has other examples.

Stress summary	Hope assessment	Caravan assessment	Assessment & locomotion summary	Resource passageway summary	Time value summary	Time management summary
Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
Some stress	LIMITED HOPE	Limited resource caravan	LOCOMOTOR DOMINANCE	An intermediate passageway	TIME	LOCOMOTOR
Positive stress	NEGATIVE HOPE	Inadequate resource caravan	ASSESSOR DOMINANCE	Challenged resource passageway	TIME	ASSESSOR
Some stress	LIMITED HOPE	Limited resource caravan	ASSESSOR DOMINANCE	An intermediate passageway	TIME	ASSESSOR

Figure 3-14: Sample of the Excel data summary (author devised)

The final assessment of Excel data was for RQ 2 which sought to identify the key resources for the parent carers and whether clusters of those resources could be recognised. After all the transcribed interviews were coded into the spreadsheet, data was analysed to examine each participant's resource strengths and weaknesses. The primary source of data was collected under the concepts of stress and hope, developed to support an assessment of the individuals resource situation, and resource passageways. However, additional data was available throughout the spreadsheet, particularly, the demographic data, assessment and locomotion, and time management.

Several resources were identified as potential key resources during coding, with resources of financial stability, social support, time, and physical resources initially identified. Cognitive ability, and psychological resources were subsequently added, and previous participants were then reassessed for these new resources. Data contributing towards

assessment of cognitive ability included statements from participants relating to their capacity to focus on complexities, their assessment or locomotion, and time-use. The final two resources added were positive mindfulness and close family support, which led to a further reassessment of all the previous transcripts for those resources. These last two key resources were assessed from the NVivo data, as well as the Excel data. The development of key resources was an iterative process of identification, and refinement through replacement, as the data was identified and entered on the Excel spreadsheet, and into NVivo.

Clusters of the nine key resources were then identified. The first cluster was formed from cases in which all key resources were adequate. This grouping was categorised as resource caravan (RC) 1, and named the adequate, effective resource caravan. The second cluster was formed from cases where all key resources were either adequate, or adequate and intermediate. This caravan, RC 2 was named the adequate to intermediate resource caravan. RC 1 and 2 accounted for most of the participants. The resource combinations for the remaining participants formed three other clusters of weaker key resources. Appendix O details the key resource situation for each participant.

Using Excel, each resource caravan was subsequently compared with the participants' resource passageway, which was also RAG traffic-light coloured. This was the focus of RQ 3, which looked at whether positive and negative resource passageways correspond to positive and negative resource caravans, and whether links to regulatory modes could be identified. The resource caravan, regulatory mode, resource passageways and time orientation for each participant are shown in Appendix K.

Conclusion

This chapter explains the research philosophy and approach. It provides an overview of the methodological approach used in this study, how the data were collected, and the considerations surrounding the approach and process. It discusses ethical considerations and the consequent approach taken towards the participants. Detail of the method and approach taken to answer each RQ is set out and explained. The chapter concludes with a table showing the data structure. Overall, this chapter provides a solid base for the following chapter, which sets-out the findings from the data collection and analysis.

4 Findings

Introduction

This study aimed to develop practical approaches to enhance parental resilience and coping mechanisms to support the well-being of parents caring for neurodivergent children. It identified two research gaps in the literature review. These gaps related to associations between COR and regulatory mode, and how the two theories might be used to support mothers caring for neurodivergent children. Understanding how the two conceptual models apply to the mothers could help identify the practical approaches; each framework considering different facets of how mothers cope, maintain, and improve their well-being. This study also considered the relevance of resource passageways, and specific attention was paid to the importance of time and social support in the mothers' lives. As the participants recruited to this study were all mothers, I will use the term mothers rather than participants when referring to findings and analysis.

This chapter builds upon the methodology and methods outlined in the preceding chapter. To help the reader understand the relevant concepts and themes, each section is accompanied by a figure that highlights the concepts and themes instrumental in establishing the findings. The chapter starts with the findings on the relationships between the frameworks. It then identifies the resources deemed significant by the participant sample and investigates whether these resources can be grouped to form distinct combinations for the mothers. The chapter goes on to report the findings on the relationship between resource passageways and current resource caravans. It then considers the roles of social support and time for mothers caring for neurodivergent children. Finally, the findings are used to identify practical interventions to enhance mothers' resilience and coping capacities.

The chapter concludes by summarising the findings.

Research findings

I first looked at how assessment and locomotion orientations relate to the conservation of resources situations in mothers caring for neurodivergent children. To answer this, I considered the data I had collected relating to each mother's resource situation, and separately, their assessment and locomotion orientation. Data for this was collected

through first order concepts and second order themes derived from the data collected in Excel. Each mother's resource situation was assessed from comments made by the mothers on their ability to deal with their stressors, and their capacity for hope at the time of the interview. Hope was used as a second component to determine each mother's resource situation because recent COR studies have highlighted hope as a resource for mitigating stress and enhancing engagement while promoting and improving psychological well-being. Hope, linked to optimism and motivation, has also been shown to be a critical force in recovery from significant stressful events.

Figure 4-1 shows a highlighted snapshot of the Excel table shown in Figure 3-13. It spotlights the concepts and themes derived from my interviews with the mother's that were used in this section of the findings.

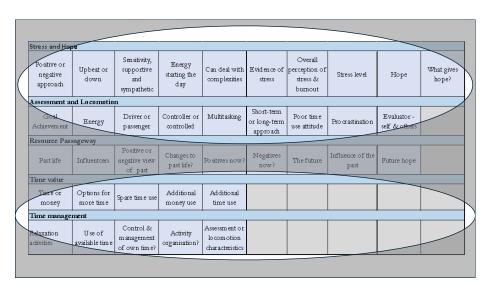


Figure 4-1: Highlights of concepts and themes used to understand how assessment and locomotion orientations relate to the conservation of resources situations

Data showed that mothers varied in their ability to deal with their stressors, ranging from an apparent ability to deal with them relatively effectively, to ineffectively. I used the term stress to capture their apparent ability to deal with stressors, adopting the label of negative stress for those who dealt effectively with stressors, positive stress for those who did not, and some stress for the remaining mothers. Hope categorisation helped to identify the extent to which mothers' saw positive prospects for themselves and their children. The

categories used were positive, limited, and negative hopes. I refer to these two resources as resource caravans, although the term resource caravan reflects an individual's wider collection and unique grouping of resources.

Mothers with negative stress and positive hope were considered to have an adequate resource situation. I refer to this as an adequate resource caravan. Mothers with some stress and limited hope were considered to have an intermediate resource situation. I refer to this as an intermediate resource caravan. Mothers with positive stress and negative hope were considered to have inadequately resourced caravans. I refer to this as an inadequate-resource caravan. These descriptions are summarised in Table 5. Data on two mothers, Luxor and Hollis, suggested they had positive stress and limited hope, but further analysis of the data on these mothers led to them being categorised as having a positive resource caravan.

Table 5: Descriptions used for Stress, Hope, and Resource Caravans (author devised)

Descriptor	Explanation of the term in this study
Stress	
Negative stress	Able to cope adequately with the stressors being experienced. It did not suggest an absence of stressors or stress.
Some stress	A position between negative and positive stress suggesting some challenges coping with routine stressors.
Positive stress	Unable to cope adequately with the stressors being experienced.
Hope	
Positive hope	Demonstration of a capacity for hope and a more positive future.
Limited hope	A position between positive hope and negative hope, either evidencing signs of both positive and negative hope, or restricted optimism.
Negative hope	Demonstration of not having a capacity for hope and a more positive future, and signs of feeling defeated.
Resource Caravan	
Adequate resource caravan	Mothers' lives and experiences were affected and influenced by a range of predominantly positive influences.
Intermediate resource caravan	Demonstration of both positive and negative influences shaping the mothers' lives and experiences.

1	Mothers' lives and experiences were affected and influenced by a range of predominantly negative influences.

Stress

This section will next review the data which led to the determination of negative stress. Mothers in this group experienced stressors, but they generally had resource caravans that appeared to allow them to deal adequately with their stressors. These mothers routinely looked for positives rather than negatives, as demonstrated in the extract

"That kind of like helps me realise my reality is not so had. Yeah, people say to me, how do you cope with five [neurodiverse children], and I just think, well, it's quite easy because if I had eight, and no money, it would be a lot worse ..." (Jupiter).

Mothers generally accepted their less than perfect lives

"...there's gonna be good times and there's gonna be s**t times and it's a case of rolling with the punches" (Ocean).

Mothers drew on diverse resources, frequently, their family

"We've got what we need, and we've all got each other. You know, I'm quite positive in that way, I suppose" (Jupiter).

They realised the importance of their own well-being

"I make more of an effort to make sure I get time to myself. I'm much better able to cope with it if I've had a bit of exercise first thing in the morning" (Clover).

Mothers discussed specific stressors, and one frequently raised was challenges liaising with formal support agencies designed to support them, such as local authorities and those in the education sector. Routinely navigating time-consuming, complex processes, with the requirement for extensive communication and dealing with poor understanding, meant that advocating for their children became a dominant stressor. Mothers routinely linked positive outcomes to their perceived personal abilities

"I put the success [fighting the education system] down to my academic ability to look at the problem analytically ... this is what I need to do to solve the problem and then having the writing skills to be able to put that down in writing, and to communicate effectively" (Clover).

Mothers protected their time through control of elements of their lives that they could influence, which included delaying aspects of their lives

"I have really good ideas about things that I want to do, but I put them on hold because I just don't have capacity to even consider them" (Jupiter).

Careers were commonly put on hold, but more positive mothers found alternative approaches for using their skills, helping them maintain their sense of value and efficacy

"I'm going to be on the preschool committee and help with their SEND [special education needs and disabilities] stuff for the other children that come in September. Doing things like that, I feel like I can be useful "(Jupiter).

Mothers categorised as experiencing some stress frequently reflected the temporal effects of both positive and negative stress, where mothers' circumstances varied, but also included situations where the situation was not clear-cut. The shifting situational nature of mothers' lives could affect their wellbeing through extended periods of loss of time and emotional resources

"Things have got difficult, partly because [of] things with my son, to the extent we are actually having a lot of support from social services and that has impacted on me emotionally a lot. So that takes up a lot of my time and affects me emotionally as well. So, I think the past month I've got very frustrated with this situation, and you know, it's taken its toll" (Callaway).

From time-to-time, the mothers' inability to control their children's situation or influence the external influences on them, could be exhausting, leading to despondency, mental, and physical stress

'When there's been a build-up of difficult situations and decisions and tiredness, that can develop into a sort of mental and physical stress, and maybe a little desperation because it's maybe being in a situation and that you have so little control over, yet you absolutely can't and wouldn't walk away from it. So, you know, it's very much out of your hands in that you have no choice but to sort of just muddle through it, and that can feel quite desperate" (Eversen).

A conclusion of some stress also resulted from cumulative stressors frequently linked to time challenges and constraints

"Stressful and tiring. The lack of time, there isn't enough time to do everything that I need to do in the day" (Bellamy).

Some mothers found it difficult to maintain focus or deal with stressors effectively

"... like it can be stressful. Often on the weekend, I'm so exhausted I just let my son watch anything on TV. I don't really care" (Hollis).

"How else do I deal with all the emotional stressful things? Well, I drink far too much alcohol, way too much ..." (Lexington).

Turning now to mothers categorised as evidencing positive stress. The data suggests that these mothers dealt with similar stressors less effectively than those recorded as having negative stress. Statements from some mothers suggest that they may have exhausted already fragile resource reservoirs, which left them without the capacity to deal with all the demands they faced. Positive stress for mothers also resulted from the cumulative effects of stigma, which could leave them feeling constantly judged on their childcare. This resulted in them adopting disengagement strategies with reduced social contact, and loss of valuable social support

"That is the struggle, and yes, its miserable and stressful, yea, this external judgment, and lack of support, lack of understanding, and then the sort of gas lighting on top ..." (Hollis).

Additional examples of data demonstrating negative, intermediate, and positive stress are provided in Appendix L.

Hope

Alongside stress, hope was another factor considered to determine mothers' resource situation. Examples of negative hope were generally unambiguous and were typically demonstrated by statements suggesting that mothers did not want to contemplate their future. This was perhaps epitomised by Kit

"I've kind of given up my hopes and dreams because there's just nothing for them right now" (Kit).

Other mothers struggled to envisage their current situation changing

'It's like there's no end to it, and that's when it suddenly hits you. It hit me after 7 years, and I suddenly thought gosh, he's not going to get better, and it's not going to be that one day it's going to be easier than this. This is my life now forever" (Lexington).

Examples of mothers' limited hope were on a continuum between positive and negative hope. Limited hope was notable in mothers with guarded approaches to what might happen, believing that by not thinking about the future, they would not need to face it

"(I'm) not looking too far ahead really" (Callaway).

Where these mothers did allow themselves to consider change, they contemplated limited changes and considered them negatively

"If I were to think about the future, how I would like it to go, then I would either like my children's needs to be lower, so they don't require as much thinking about on their behalf, or I'd like to work fewer hours, to take the pressure off a bit, but that's not going to happen" (Clover).

Many mothers were able to envisage things could improve, suggesting positive hope

"I guess I can think it's not always going to be this stressful" (Bellamy) and

"But now we know we have a label, and that really isn't a bad thing, because a label can open doors" (Honor).

Positive hope was commonly linked to cumulative advantage through the mother's resource passageways

"I Just think I have a psychological makeup that refuses to be broken is probably what allows me to have any hope. [from] A generally positive background really" (Arden).

Resource passageways prompted mothers to emulate the approach taken by their parents

'I've never really had anything to be negative about. I've had really supportive parents who did everything they could for me and that's what I've tried to do for my children" (Kingsley).

This suggests that mothers' resource passageways were relevant to their current positivity and influential in their hope for the future.

Additional examples of data showing positive, intermediate, and negative hopes are presented in Appendix M.

Regulatory mode

RQ1 also sought to understand how an individual's assessment and locomotion orientation at a specific time were related to their resource situation. Therefore, it was necessary to determine the regulatory mode (RM) for each mother. The following sections consider mothers' RM orientation.

RM assumes that assessors focus on determining the optimal goal and the method for achieving it. Locomotors focus on achieving their goals quickly and successfully. I determined each mother's assessment and locomotion orientation using the statements recorded in Excel. To determine the orientations, I referred to the characteristics and emphases for each orientation that I had extracted and codified from prior literature, examples of which are shown in Appendix J.

Descriptions of assessment, locomotion, and mixed orientations are summarised in Table 6.

Table 6: Descriptions used for assessor, locomotion, and mixed-mode orientations (author devised)

Descriptor	Explanation of the term in this study
Assessment and Locom	otion
Assessor dominance	Mothers had a dominant assessor orientation. A focus on determining the best goal to strive for and the optimal way to achieve it.
Locomotor dominance	Mothers had a dominant locomotor orientation. A focus on moving from their current state to a desired future state for goal achievement.
Mixed assessor & locomotor orientation	Mothers demonstrated a mix of an assessor and a locomotor orientation. Both assessment and locomotion are needed for goal achievement, and neither orientation was dominant.

Assessor orientations

The priority for assessors is how to achieve rather than achieving. This may result in tasks that are not progressed or completed. Merritt refers to her procrastination and unfinished tasks, typical of an assessor orientation

'It always has been the perfection and the accuracy, but that's what leads to me procrastinating a lot. I find it hard to start a job because I know I won't have time to finish it properly. So therefore, I don't start it, so I'm not sure if it's perfectionism or if it's a fear of failure" (Merritt).

Assessors limited goal focus can result in them moving from task-to-task, with little desire to progress or complete what they start

"[I am] very easily distracted. I'll start a job and then I'll tidy a table, and then I'll find something on the table that reminds me that I've got something today, so I make the phone call for that, and then I realise that the phone needs something, and I'll go and do something with the phone, which takes me to the kitchen and then I'll clean the top and then I come back in and I think I'll have a cup of coffee 'cause the kettle's in front of me because I can see it' (Merritt).

Locomotor orientations

Locomotors focus is on progress and goal achievement

"It's just getting it done" (Jupiter).

Mothers demonstrated locomotor tendencies by using techniques to manage their time, avoiding non-achievable tasks, and choosing more achievable goals or subgoals

"I will literally write a list of what I'm doing but do something else that I think needs doing as well and add it to the list and cross it off, so that I can see I've done things, but I'm also recognising I've done things by adding it to the list and crossing it off" (Jupiter).

Locomotors typically want to organise and control their own and other people's lives

"I've got rotas, I've got lists and timetables on our wall, so everybody has a time where they make their lunch, time slots so they know which order to do it in" (Jupiter).

Mixed locomotor and assessor orientations

Although a locomotor or assessor orientation is normally seen to be dominant, effective goal achievement requires both assessment and locomotion. While most mothers demonstrated orientations towards one or the other, a few demonstrated a mixed orientation. Honour was one of the mothers. She discussed organising an event with friends, saying she could organise, but would not act if she did not need to

'I am terrible at it, and I hate doing it. I think it's because I need to plan so much for the family. I really hate doing more of it, which is why I end up not seeing people that often, because unless someone organises me, I just don't do it' (Honor).

Some mothers demonstrated mixed assessor or locomotor tendencies related to her situation, highlighted by differences in their approaches at home and work

"At home I feel like I have to kind of get on and do stuff, to keep me going. In my personal life, I'm not that organised. No, not really organised at all" (Luxor).

My analysis established different approaches to task management and goal achievement, identifying orientations of assessment, locomotion, and a combination of the two.

I identified a significant number of mothers with adequate resource caravans and locomotion orientation. This suggests an association between a well-resourced caravan and locomotion orientation in mothers caring for neurodivergent children. Three mothers with inadequately resourced caravans had mixed assessments and locomotion orientations, indicating an association between a mixed regulatory mode and an inadequately resourced caravan. However, the latter association was based on only three mothers.

Table 4.7: RQ1: Mothers assessor, locomotor orientation, and resource caravan (author devised)

Participant	Stress Assessment	Hope Assessment	Resource Caravan Assessment	Assessment and Locomotion Orientation
LUXOR	Positive stress	LIMITED HOPE	Inadequate resource caravan	MIXED
KIT	Positive stress	NEGATIVE HOPE	Inadequate reso urce caravan	MIXED
HOLLIS	Positive stress	LIMITED HOPE	Inadequate resource caravan	MIXED
BRIGHTON	Some stress	LIMITED HOPE	Intermediated resource caravan	MIXED
KINGSLEY	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
JUPITER	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
HONOR	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
HALSTON	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
EVERSEN	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
CYPRESS	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
ARDEN	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
LANDRY	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
Bellamy	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
OCEAN	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
CLOVER	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
BRIAR	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE
LEXINGTON	Some stress	LIMITED HOPE	Intermediated resource caravan	LOCOMOTOR DOMINANCE
MERRITT	Positive stress	NEGATIVE HOPE	Inadequate reso urce caravan	assessor dominance
CALLAWAY	Some stress	LIMITED HOPE	Intermediated resource caravan	assessor dominance

An association between resource caravan type and assessor orientation could not be identified from my analysis, which produced conflicting results. In addition, four of the mothers (Brighton, Lexington, Merritt, and Callaway) did not conform to any of the identified resource groupings. However, there is no clear reason for this discrepancy. Each

of the four mothers' regulatory modes (RM) was resolutely assessor or locomotor, apart from Brighton, who appeared to have a definite mixed orientation. My analysis identified nothing to link the mother's education level, life balance, work situation, partnership status, social life, health, or the complexity of their children's needs. The only factor differentiating the mothers was age, as Lexington, Merritt, and Callaway were three older mothers and Brighton was the youngest. The results of my analysis are tabulated in Appendix N. I concluded that the three must stand outside the resource caravan and the regulatory mode groupings that I identified.

Table 4.8: Mothers whose groupings of stress, hope, resource caravan, and regulatory mode could not be linked with the identified combinations (author devised)

Participant	Stress Assessment	Hope Assessment	Resource Caravan Assessment	Assessment and Locomotion Orientation
BRIGHTON	Some stress	LIMITED HOPE	Intermediated resource caravan	MIXED
LEXINGTON	Some stress	LIMITED HOPE	Intermediated resource caravan	LOCOMOTOR DOMINANCE
MERRITT	Positive stress	NEGATIVE HOPE	Inadequate resource caravan	ASSESSOR DOMINANCE
CALLAWAY	Some stress	LIMITED HOPE	Intermediated resource caravan	ASSESSOR DOMINANCE

Table 4.7 summarises my assessment of each mother's stress and hope, from which I derived their resource caravans. My assessment of each mother's regulatory mode (assessment or locomotion) orientation is shown in the right column.

The preceding section explains how participant data addressed how assessment and locomotion orientations relate to the conservation of resources situations. It demonstrated the approach to establishing mothers' resource caravans and regulatory modes to determine whether a link can be established between the two for the mothers in this study. In summary, my analysis suggested an association between an adequately resourced caravan, locomotion orientation, an inadequately resourced caravan, and a mixed assessment and locomotion orientation.

Using the combined lens of assessment and locomotion, and conservation of resources, I next looked at whether key resources and common groupings, or caravans of these resources, can be identified for mothers caring for neurodivergent children.

An individual's need for resources is influenced by their personal situation. However, individuals may have a greater need for specific resources, perhaps contextually or because of their resource caravan passageway. COR theory argues that this need will be objective, as other individuals in a similar situation are likely to need comparable resources. Identifying key resources may point to generalisable and important resources for mothers caring for neurodivergent children. Data for this question was collected in Excel, identifying resources that were important in mothers' daily lives. Statements highlighting the resources were both discussed and implied by the mothers.

Figure 4-2 shows a highlighted snapshot of the Excel table shown in Figure 3-13. It spotlights the concepts and themes derived from my interviews with the mother's that were used in this section of the findings to understand whether key resources and common groupings, or caravans of these resources, can be identified.

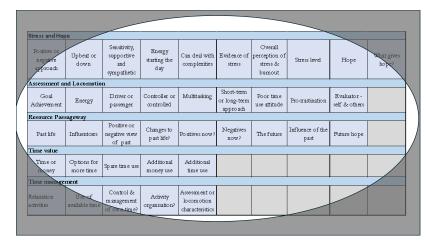


Figure 4-2: Highlight of concepts and themes used to understand whether key resources and common groupings, or caravans of these resources, can be identified

Nine key resources were identified as prominent and significantly influential in mothers' lives. Some resources were explicit and related to the mother's financial situation, social support, time, and health. Other resources: cognitive, psychological, mindfulness, personal skills, and immediate family support, were more implied. For example, mothers referred

to their financial capacity to make essential or luxury purchases to pay for their children's education. Social resources were noted in friendships, work networks, family relations, and social activities. They were also identified by the help, advice, opportunities, and support derived from these connections. The restrictions or freedoms that mothers had over their time and their approach to making the best use of it were frequently discussed. The overall importance of time was evident. Although most mothers were generally upbeat about their health, several spoke of the functional limitations due to menopause, depression, and anxiety. Where personal health was challenged, it was rarely a minor issue for mothers and its impact was notable.

Other resources influencing mothers were generally implied in comments stories and descriptions. For example, some mothers were explicit in their identification of psychological resources from descriptions of their personalities, adaptability, and proactive approach. Self-descriptions by others were less clear. These were frequently linked to how they tackled and managed their challenges and goals, providing more implied demonstrations of their psychological resources. Similarly, cognitive resources were often mentioned explicitly but were more frequently implied. Data was derived from mothers' involvement in activities requiring diverse cognitive capacities, or discussions about activities requiring varied cognitive capabilities. Personal skills were generally implied from statements about their ability to deal with either routine or complex issues, and how they arbitrated on their children's behalf.

The next section uses quotes from mothers to explain the determination of the nine key resources. Quotes related to mothers' financial situations, social support, time, health, cognitive and psychological situations, mindfulness, personal skills, and immediate family support.

Mothers described freedoms and restrictions from their financial situation. Mothers' expectations of an adequate financial situation varied significantly. Earned income is frequently augmented by grants, credits, and allowances. Hollis explained how her monthly income left little to spare after her rental payment

'I work 15 hours as it's all I can do in my circumstances looking after my child. My income is a little over 900, but my rent is now just under 800' (Hollis).

Effective support networks were referred to by mothers with their close and wider family, old and new friendship groups, and at work. Close networks often focus on a few intimate friends who provide efficacious help and support. Honor explained her close positive supportive social network

T've got a network of a couple of other mums whose children are also neurologically diverse, and we just catch up and either drink wine or go for a meal, ..., the [their] children are different from my children. And so, it's communicating with other people and just having a crutch to lean on, and you know, that really helps, because a lot of people don't understand' (Honor).

Time was the resource most frequently lacking, although this was not constant. Mothers linked time to themselves, childcare, family, and their general life situations. Merrit discussed the challenges in finding time to be sensitive and supportive to her family.

'... There are times when it becomes just too much, and I then end up prioritising Susie ahead of the rest of the family. I do know that they are affected by that but it's all I can do at times' (Merrit).

Poor health was rare; however, several mothers were negatively affected by their mental and physical conditions, which disadvantaged them. Menopause, mental illness, depression, and diagnosed or self-diagnosed neurodiversity were the most frequently mentioned. Hollis mentioned how health factors affected her ability to function effectively

I feel like I'm entering menopause, and I've had blood tests to confirm it. I'm on HRT to help with like mood issues because they can be worse certain times each month' (Hollis).

Cognitive resources were associated with mothers' capacity to think through complexities, rationalise thoughts, and respond effectively to problems surrounding their own or their children's issues. This affected their ability to rationalise the challenges and determine where to focus efforts for the best effect. Arden mentioned focussing her attention on challenges and problems she was most likely to be successful with

'A lot of the complex issues that we are dealing with have no resolution. So, things like how to access social care that is going to meet George's needs. There isn't any and we spend a lot of time thinking about innovative ways, but there just isn't one because there aren't the solutions enough. You have to really pick your battles' (Arden).

Psychological resources considered the mothers' personal mental strengths and perceived or actual psychological problems. Inadequacy was also suggested by statements suggesting a reduced ability to deal with stressors. Kit reflected negatively on her need to routinely spend time alone

I need time away from pretty much everyone just to regulate myself. It means we have very little time to spend as a family' (Kit).

Mindfulness has emerged as an important resource. It incorporated mothers' attitudes towards their experiences, judgement, contentment, and acceptance of their current situation. Landry referred to an evolving, more positive sense of well-being about her situation, awareness and engagement

I'm okay now. I start every day with a positive mindset". "But now I don't feel like I'm on a constant treadmill of having to fight everything, which is what life was like. [Now] I'm in a place where you can react to things in a more laid back and sort of measured way" (Landry).

Mothers linked their personal skills to their intellect and education. These skills were frequently associated with the ability to advocate for children as well as their general ability to cope. Clover explained her success in tackling the challenges of the education system.

"... [I'm at a] bit of an advantage when it comes to fighting the battles against the system ... I put the success down to my academic ability to look at the problem analytically. You know, this is what I need to do to solve the problem and then having the writing skills to be able to put that down in writing and to communicate effectively by email' (Clover).

Finally, immediate family support, rather than wider family support from grandparents and siblings, has emerged as an important psychological, emotional, and practical resource. Brighton explained that although she and her husband were separated, his support allowed her respite from pressures and demands, creating self-time

'Me and their dad co-parent really well now. So, he lives in the same village. So, I get 2 days off each week, and not necessarily the same two days. But because of the dynamic that he and I have, that's like my reset. So, like he'll have the kids say on a I don't know, Thursday, Friday. So, I haven't got that school run and putting them to bed and their tea. I actually get like couple of hours, right, to get to sit and do something for myself' (Brighton).

The resources for each mother are shown in Appendix O.

Having established findings on whether key resources and common groupings, or caravans of these resources, can be identified, I sought to establish whether common groupings or caravans of the nine key resources could be identified. I developed four groups of key resource clusters. The first group was a resource cluster with an adequate level for each resource. The next group was a cluster with either adequate or limited resources. I identified two additional groups, the first of which comprised adequate, limited, and inadequate resources. It had stronger cognitive, financial, health, and immediate family

support. The last group consists of a cluster of predominantly inadequate resources. The cluster of resources for one mother did not align with any of the groups identified. The resource groups portrayed the resource caravans of key resources for each mother, plus one individual cluster of key resources. I assigned descriptors to each caravan to reflect the characteristics that made them distinctive.

Figure 4-3 shows the four identified resource caravans or clusters. Each caravan's resource cluster was summarized by reviewing adequate, limited, and inadequate resources, forming the basis for its name. Caravan 1, comprising all adequate resource cases, was named the adequate and effective resource caravan. Caravan 2, a mixed cluster of adequate and intermediate cases, became the adequate-to-intermediate resource caravan. Caravan 3 represented the individual mother with a mix of adequate, intermediate, and inadequate resources, having weaker financial, mindfulness, and immediate family support. Caravan 4 was a mixed resource caravan with stronger cognitive, financial, health, and immediate family support. The fifth grouping, Caravan 5, was a predominantly inadequate mixed-resource caravan.

Legend for colour coding

Adequate

Adequate or intermediate

Intermediate

Intermedite or inadequate

adequate

Resource Caravan 1

Adequate, effective resource caravan

Cognitive	Financial	Mindfulness	Health	Social	Psychological	Personal Skill	

6 individuals

Resource Caravan 2

Adequate to intermediate resource caravan

Cognitive	Financial	Mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support

7 individuals

Adequate cognitive and health resources

Adequate or intermediate financial, mindfulness, social, psychological, personal skills, time and immediate family support

Resource Caravan 3

Mixed resource caravan with weaker fanancial, mindfulness, and immedaate family support

Cognitive	Financial	Mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support

1 individual

Adequate health, social and time resources

Adequate or intermediate cognitive, psychological and personal skills

Inadequate financial, mindfulness, and limited family support

Resource Caravan 4

Mixed resource caravan with stronger cognitive, fanancial, health, and immediate family support

Cognitive	Financial	Mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support

3 individuals

Adequate cognitive, physical, and immediate family support resources

Adequate or intermediate financial resources

Inadequate or intermediate, social and personal skills resources

Inadequate mindfulness, health, psychological, and time resources

Resource Caravan 5

Predominantly inadequate or mixed resource caravan

T Tedominion	made quare o	i iimirea resource ei	41 64 7 64 11					
Cognitive	Financial	Mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support

2 individuals

No strong resources

Intermediate cognitive, health, and personal skills

Inadequate or intermediate financial, and social resources

Inqadequate mindfulness, pshchological, time, and immediate family support

Figure 4-3: The five resource caravans identified (author devised)

The derivations of each caravan supported by the mothers' statements are explained in the following section. A mother representative of each caravan is used to describe its characteristics.

Resource Caravan 1

Six mothers were clustered to form caravan 1. All had adequate levels for each key resource. The mothers' ages ranged from 36 to 45 years, with a mean age of 40.6 years, compared to the mean of 45.1 for all mothers. Five mothers were married, and one was divorced but in a long-term relationship. All were employed or self-employed, either full-time or part-time, and were considered to have no financial difficulties. They had between two and five children, ranging in age from 20 months to 24 years, and most, but not all, of their children were neurodivergent. Several children had comorbidities including paraplegia. Social support was effective for all mothers, and all but one spoke about living in an effective community. All had a good life-course and resource passageway.

Appendix P shows the quotes from Halston related to each of the nine key resources. Halston was typical of the mothers with an adequate balanced resource caravan. She had two boys. One was 11 years old diagnosed in 2020 with attention deficit hyperactivity disorder (ADHD), anger management issues, and anxiety, and the other child was 9 years old, diagnosed in 2022 with ADHD and Autism. Halston worked full-time in a job that she found challenging, and she had immediate family support from her husband, who was involved in caring for their children

'We try to share the responsibilities; my husband can get flexible time at work and does come home to meetings if both of us being involved will be useful' (Halston).

Halston felt her family had no financial difficulties. She had a positive approach to life, which was partly aided by her effective social networks. While her profile demonstrated an adequate level of resources in each domain, challenges were not absent from her life.

Resource Caravan 2

Caravan 2 was the most common grouping of key resources, clustering mothers with mixtures of adequate and inadequate levels of the nine resources. Adequate resources in the caravan were cognitive, health, social, and personal skills, and immediate family support. There was a more mixed profile of financial, mindfulness, psychology, and time.

Briar demonstrated a typical profile for mothers of this resource caravan. She had an autistic daughter aged 13 years who had chronic fatigue syndrome. She had a son aged 8 years awaiting assessment for autism and ADHD. Both children were unable to attend school and were at home, undertaking online education.

Briar worked freelance from home and was helped with childcare by her husband, who was employed full time. Recently diagnosed with autism, Briar demonstrated adequacy in six of the nine key resource domains but limitations in mindfulness, psychological, and time resources. She appeared to have had a challenged. She mentioned her undiagnosed autism. She said that the impact of her challenged background and undiagnosed autism led her to do all she could to ensure her children were not subject to the difficulties she had experienced. She worked part-time on several committees. These commitments affected her time availability, and she talked about struggling to manage everything she needed to do. Her time challenges were exacerbated by her autism, for which she routinely took time away from others including her family. Briar spoke of her psychological challenges, despite taking positive action to address them

"I try and be positive, but I don't always feel very positive, but hey, we are where we are, and it is what it is". "I've done a lot of work and therapy to be able to utilise these things in a positive way" (Briar).

Appendix Q shows quotes from Briar, which are demonstrative of a resource caravan 2 profile.

Resource Caravan 3

Caravan 3 represented a single mother who had a combination of adequate, limited, and inadequate resource levels. Appendix R shows this caravan for Callaway, a divorced mother without immediate family support who worked part-time advising families with autistic children. She had a daughter aged 17 years and a son aged 15 years, both with autism. Her son had recently been violent towards his mother and sister, initiating social service interventions. Her daughter attended a specialist school. The son was in mainstream education.

Callaway's resource combination could not be matched with that of other mothers. She made statements indicating she had adequate health, social, and time resources but inadequate resources for finance, mindfulness, and immediate family support. Callaway

lived alone with her children, appeared to have minimal communication with her son who avoided her, and had a daughter to whom she provided extensive support. Her limited engagement and focus on her present challenges and her negative self-image suggested limited mindfulness. More positively, she made no reference to any issues with time availability or health and spoke about several social networks.

"...extensive support network, friends, face to face, and online, weekly, and church, I would go to church at least three out of four weekends in a month" (Callaway).

Resource Caravan 4

Caravan 4 represents a grouping of mothers with a mixture of adequate, limited, and inadequate resources. Merritt was a member of this group. Her resource cluster had a combination of both adequate and inadequate resources. The other two mothers with this caravan also demonstrated limitations in some resources. Merritt was married and worked 0.8 whole-time equivalent hours in employed work. She was supported in her childcare by her husband, who worked full time. Merritt was diagnosed with ADHD, had an undiagnosed, but suspected neurodivergent son, and two daughters, both diagnosed with different neurodiverse profiles, as well as a range of mental and physical comorbidities.

Merritt provided comments which indicated she lacked mindfulness, psychological and personal skills, and time resources. Her cognitive resources appeared to be adequate, as she could tackle everyday tasks and problems, and approach them using structured and effective techniques. Her financial and immediate family support was adequate. However, Merritt lacked time, and social support

"Everybody's drifted away" (Merritt).

She was on sick leave when interviewed, and although there was no suggestion of physical health problems, she appeared to be psychologically challenged. Merritt appeared to be poorly engaged, had negative focus, and struggled with her current situation. She had immediate family support from her husband, with whom she aspired to have more time.

"I'm kind of hoping we'll [she and her husband] just gravitate more to each other because we don't get the opportunity very often at moment" (Merritt).

Caravan 4 is a mixed resource caravan, but with stronger cognitive, financial, physical, and immediate family support. The overall cluster of resources demonstrates the compromised

resource situation of this group. Appendix S shows the resource situation of Merritt as an example of a mother forming this group.

Resource Caravan 5

Resource caravan 5 is dominated by inadequate and limited resources for the nine key resources. Although, at first sight, the profiles of the two mothers in this grouping differed, the combinations were congruent. Both mothers had inadequate or limited financial, mindfulness, social, psychological, and personal skills, time, and immediate family support resources. In the remaining two domains of cognition and health, both demonstrated limited or adequate resources.

Hollis demonstrated this caravan's resource cluster. She was a single mother who had been alone for over 12 months, following what appeared to be a short-term relationship, and was significantly reliant on her mother who lived nearby. She was employed for 12 hours per week. She was neurodivergent. She had a son aged 9 years who was diagnosed with ADHD and autism. Her son was challenged by separation from his mother and changes to his routines. He was medicated to help with concentration and to calm him.

Comments by Hollis indicated she focussed significant time and effort on her son, working a few hours four days a week in the mornings to allow her to commit to her son after collecting him from school before lunch. Statements on her cognitive resources were mixed

but she struggled to relax, whilst routinely needing to take time-out

"... often it's just easier to lie in front of the TV" (Hollis).

A comparatively strong resource for Hollis was her physical health. She referred to swimming but offset this by negative comments about menopausal problems and weight control issues. Hollis suggested inadequacies in seven of the nine key resources. She described financial challenges, and issues with mindfulness, evidencing some self-awareness, but challenged by unmet expectations, routine resentment, and disappointments, notably, social and psychological challenges

"Unfortunately, because of my way of communicating sometimes people think I'm rude, so I've been removed from certain groups that I've found supportive. I find that hurtful. It'd be nice to have someone to talk about things face to face. All I want is someone I can empathize with, to say right, you know, I would feel the same" (Hollis).

She mentioned time challenges in several contexts. It was difficult to identify data to demonstrate positive personal skills. She made frequent references to needing help and support for her own and her sons' neurodiverse issues. Her immediate family consisted of herself and her son but with wider family support from her mother. However, she made statements indicating that her mother lacked understanding and empathy:

"... unlike my mum or sister who would [will] just tell me I'm being unreasonable" (Hollis).

The Hollis profile reflects an inadequate and limited cluster of resources, as shown in Appendix T. This chapter next considers how positive and negative resource passageways for mothers caring for neurodivergent children relate to current positive and negative resource caravans and whether links to the individual's regulatory mode be identified.

COR theory describes the concept of resource passageways. These are the conditions developed during people's lives that reinforce, advance, enhance, and safeguard their resources, or conversely, undermine, weaken, prohibit, or drain their resources. Individuals with fragile or inadequate resource passageways are more likely to struggle with stressors. This is because their limited resource reserves restrict their capacity to cope with stressful situations. This can also increase vulnerability to negative feelings and thoughts. Resource limitation, and conversely, resource advantage, may affect an individual's approach to and capacity for self-regulation. Similarly, regulatory mode orientation may influence their ability to conserve and generate personal resources.

Figure 4-4 shows a highlighted snapshot of the Excel table shown in Figure 3-13. It spotlights the concepts and themes derived from my interviews with the mother's that were used in this section of the findings to consider how positive and negative resource passageways for mothers caring for neurodivergent children relate to current positive and negative resource caravans and whether links to the individual's regulatory mode be identified.

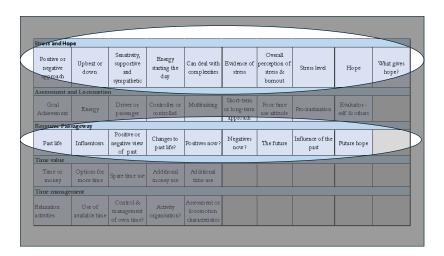


Figure 4-4: Highlight of concepts and themes used to consider how positive and negative resource passageways for mothers caring for neurodivergent children relate to current positive and negative resource caravans and whether links to the individual's regulatory mode be identified.

I established each mother's resource passageway and established whether links could be identified with their resource caravans which had been determined in an earlier section. Judging how positive and negative resource passageways relate to current positive and negative resource caravans and whether links to the individual's regulatory mode be identified, required an assessment of the findings of any links with the mothers' regulatory modes.

Since resource passageways evolve throughout people's lives, I reviewed each mother's early years, adulthood, and current lives. I also considered any challenges they experienced and the interventions they had taken to affect their life courses. This helped me to understand their life courses and resource passageways. I used the age at which they could have gone to or did go to university, to separate early years and adulthood, as this appeared to be a significant juncture for many mothers.

Mothers described various passageways which had resulted from their childhood experiences or that developed during their lives to influence their current resource situation. Individual resource passageways could be grouped into discrete passageways. Four passageways were identified. I describe these as empowering resource passageways, opening resource passageways, limiting resource passageways, and restricting resource passageways. These descriptions and my explanation of my nomenclature are in Table 4.9.

Table 4.9: Resource Passageways (author devised)

Descriptor	My explanation of the term in this study
Empowering Resource Passageway	A passageway that began with positive stable childhood experiences and provided advantages that could be developed and enhanced during the individual's life journey. In this respect the positive experiences and advantages empowered the mothers to develop their lives constructively.
Opening Resource Passageway	A passageway that opened-up, beginning with a less positive start, but developed more positively (through interventions such as the development of a positive mindset and actions, or through therapy). The Passageway demonstrates how mothers with restricted early passageways could develop an adequate balanced, or a balanced weaker resource caravan, described in RQ2.
Limiting Resource Passageway	The mother's early life was in some way constrained and fell-short of providing the mother with the advantages and positive start of an empowered resource passageway. The limitations continued into adulthood.
Restricting Resource Passageway	This passageway described a life course initiated with a childhood that provided little if anything that could be described as positive or advantageous. The passageway progressed into and through adulthood in a similar restricted vein and resulted in a limited or inadequate resource caravan.

A comparison of the experiences of the mothers enabled me to align each of the four passageways with the five resource caravans I identified earlier. Appendix U shows quotes from mothers in each passageway regarding their childhood, adulthood, and current lives. The next section reviews each of the four developed resource passageways.

Empowering resource passageways

The empowering resource passageway was associated with resource caravans 1 and 2, which were the most advantaged resource caravans. All the mothers forming resource caravan 1 and most of the mothers forming resource caravan 2 demonstrated an empowering resource passageway. An opening resource passageway was identified in three other mothers in resource caravan 2 demonstrating their development from a relatively restricted early life to a comparatively well-resourced adequate to intermediate resource caravan (caravan 2). The significance of this is that all mothers in the better-resourced

resource caravans 1 and 2 were associated with a resource passageway that was either positive throughout their life or developed to be more positive during their life course through an opening resource passageway.

Mothers with an empowering resource passageway mentioned common aspects of their childhoods, immediate and wider family, and external factors, which acknowledged the importance of family units and life experiences. Having a stable and close family, supportive parents, and their perceived positive presence were frequently mentioned. Siblings and being close to their brothers and sisters were often referred to. Also important were the wider family, particularly grandparents, and the positive consequences of these relationships. Being socially active with positive non-family associations, such as supportive teachers, formal youth organisations, and more generalised local community links, were mentioned by several mothers. A closely supportive family was the dominant feature.

Mothers referred to common positive components during their adult life, which were factors both within and outside the home that emphasised the importance of family, friends, and social contacts both inside and outside the work environment. They frequently mentioned their marriage and partner relationships, their home-building, and their children and families. Outside the home, positive comments centred on their work, careers, friends, and community.

In the mother's current lives, positive factors related to their immediate and wider family and their own positivity. They acknowledged their past family lives and positive social experiences outside of the family unit. Supportive husbands or partners and the positive impact that their children could have on them featured strongly. Several mothers mentioned having constructive mother-child relationships. Mothers frequently mentioned the positive learning they gained from caring for their children, feeling that their experiences had improved them as individuals

"I feel I'm a better person because of everything that Alan and I have been through together. I think caring for him has taught me so much and it's made me a better person, so I love having him in my life" (Ocean).

Mothers also made statements about their hopes and plans for the future. They frequently mentioned actively trying to ensure that their children had a positive life and felt valued

and useful. Contributory factors to this included mothers' upbringing and background and the role models that their parents had been for their own family

'I've never really had anything to be negative about. I've had really supportive parents who did everything they could for me and that's what I've tried to do for my children" (Kingsley).

Hope came from their positive attitude and approach to their own lives and close families. Comments were linked to effective, wider family networks. This was particularly so for close relationships with their own parents (generally their mothers) and emotional and practical support received from their siblings. Taking time for themselves was common, whether for exercise, socialising, or general well-being. This suggests the overall impact of the life-course of mothers associated with their empowering resource passageway developed self-confidence and eudaimonism through wellbeing, personal fulfilment, realisation of their personal potential, and frequently, from supporting others

"One of the things I was looking at doing in the future was studying again in community brokerage, you know, supporting people to find out their options for self-directed support and things. They said I'm a good peer connector can talk to people almost effortlessly. I'd never really thought about it like that, but I suppose I do" (Ocean).

Opening resource passageways

The next passageway I derived was an opening resource passageway. Comments on their current lives by mothers within this group demonstrated significant improvement throughout their lives. They generally described experiencing a challenging start in their life. However, each had developed more positive resource caravans, often by actively taking control of their lives. They developed a relatively optimistic approach and outlook, with hope for themselves and their children. The life journeys and resource caravans at the time of the interviews varied. Although one mother's resources were challenged in five of the nine key resource domains, her inclusion within this group, as with the three other mothers, was fitting.

Data linking the life courses of mothers with an opening resource passageway centred on their negative childhood experiences, acknowledgement of their psychological challenges, and actions taken to understand and address those challenges. Most mothers said that they were neurodivergent, although only one was diagnosed. One reported having mental and physical health issues, and two reported having extensive therapy during their lives and

taking antidepressants. More positively, one discussed working to develop selfunderstanding, and another spoke about formal mindfulness training she had undertaken and benefited from

"Then I've subsequently trained to be a mindfulness teacher. Which, yeah, yeah, we, which is an amazing. I think mindfulness offers amazing benefits to many people who have lives with so many things outside their control. Certainly, as a parent with neurodiversity children with lives they can't control" (Landry).

The mothers talked about using their negative experiences with their fathers to be positive toward their own families. One mother spoke about using her past and later positive experiences to better understand and help others: a mindfulness trait.

The current lives of mothers in this group were generally far from ideal. However, their inclusion in the cohort demonstrating an opening resource passageway highlights the development of their life course from a challenging beginning to a relatively more enabling current life. They achieved this through actions that generally resulted from self-awareness and help. These mothers continued to take steps to address their issues and improve their lives.

Limiting resource passageways

The next resource passageway I identified was the limiting resource passageway. Two mothers formed the group conforming to this passageway. While their childhood was not notably challenging, neither were they positive. One mother said she dwelled on her negative memories, and the other said that sad things dominated her childhood memories. Both mothers cited the deaths of key figures during childhood as important events, either their fathers or grandfathers. One mother said her family was close during childhood, but both mothers recalled being bullied by older brothers, the effects of which still negatively affected them

"My brothers they're like 5 and six years older, and they were quite bullying to me, and thinking back, I think that did shape a lot of who I am now. I sort of think twice about doing things, it damps down my enthusiasm now. And yeah, a lot of things I would have done if I think, if they didn't have the influence they did?' (Callaway).

Schooling left negative memories for both mothers, but they identified going to university as a positive event. One said her life opened-up during her 20's and 30's and mentioned

positive career opportunities and experiences during that time, suggesting a degree of balance between the positive and negative memories

"There's enough positive to sort of outweigh the negatives, I think. Yeah, from university I had a great time, I had a great job, I had great car. I'm thinking about my late teens through to my 30's, but I suppose I think of those things as slightly superficial, and I wouldn't say that they're important to me, but they of course they were" (Lexington).

Neither mother had been able to draw on support from a husband or close partner for over 10 years, although both spoke of having support from people outside their immediate family. Also important for both mothers were their neurodivergent children. The children had been and continued to be the focus of their lives. The mothers had significantly adjusted their careers to allow them to provide what they considered to be appropriate levels of care for their children.

In summary, the lives of the two mothers with a limiting resource passageway identified several elements that restricted them from developing their full potential. However, numerous aspects provided them with potential and opportunity. In this respect, their lives were not empowering, and neither had they developed into an opening resource passageway. However, their life course cannot be categorised as having restricted resource passageways, which is the passageway described next.

Restricting resource passageways

The restricting resource passageway was identified in three mothers, all of whom spoke about their parents' relationship issues when the mothers were children. Each attributed their parents' problems to one or both parents having autism. Two of their parents had divorced. One had subsequently separated from the second husband. One mother recalled experiencing stress from parental arguments during childhood. Another considered her mother to be a narcissist who was unresponsive to her needs and feelings, and one felt that her father had been controlling and rarely complemented her. This suggests a degree of family dysfunctionality and poor parental empathy in the mothers' childhoods. Hollis summarised this

"My parents arguing and my dad threatening to leave on a regular basis. I think both my parents are on the autistic spectrum and that caused a lot of communication issues between them and the way they reacted to certain challenges was not necessarily very healthy" (Hollis).

Perhaps because of the breakup of their family units, two mothers had lived with their grandparents who they found emotionally distant or strict and controlling. In one case, the grandmother experienced depression. Two mothers mentioned people external to their immediate family as key individuals rather than their parents. This finding suggests that their parents fell short of being role models.

Two of the mothers had accepted significant responsibility during childhood, speaking about caring for siblings or siblings and mothers, from a young age. The other mother had moved from her parents' home to self-care by age 16 when she was referred for social worker intervention. This suggests an early family life that neither she nor her parents wished to prolong. Schooling was negatively mentioned in the recollections of all three mothers, with stories of being bullied, picked on, or feeling excluded. Two were explicit about their poor or limited performance at school, and one reported hating school. This adds to the suggestion of a challenging childhood.

Mothers' challenges continued throughout their adult lives. Comments were made about mental health and neurodevelopmental conditions, with two mentioning autism and the other, depression. This led one mother to say she had felt uncomfortable throughout her life

"... if I'd had a diagnosis of Aspergers say in university, I think that could have helped me greatly" (Kit), "I just thought it was normal to be uncomfortable" (Kit).

Notably, people in the autism spectrum are more likely to experience anxiety, depression, and an increased risk of mental health conditions compared to the general population. Another mother spoke of her psychological issues and depression leading to counselling, long-term medication, and, subsequently, social services involvement. Two of the mothers also referred to their menopause.

The two married mothers mentioned that their husband's support was important, but a common thread for the mothers was their limited friendships and social connections

'It's the lack of support structures and lack of awareness and understanding from people around me" (Hollis),

and lack of community involvement

"[A] Local community doesn't exist" (Merritt).

Similarly, there was limited wider family involvement or support

"I do have siblings but although if something awful happened, they would be here in a trice, we're not in each other's pockets and it would be alien for me to ring up and say I'd had a terrible day because of the children or whatever, that's just not what we do. So, it really is just my husband and I and he's in the same boat. He has no one either. We've just got each other" (Merritt).

Restricting resource passageways were linked to combinations of life course effects, health, and neurodevelopmental conditions. The corollaries of those factors resulted in their more restricted resource caravans. Merritt talked about her current life

"What else for positives? I'm still on this planet, and I haven't shuffled off. I think I'm quite fortunate to still be around, having been very depressed in recent times" (Merritt).

Linking resource caravans and resource passageways

The relationships between the mother's resource caravans and passageways are summarised in Figure 4-5, which shows a framework of the connections between each of the five resource caravans previously noted and the four resource passageways identified. For ease of reference, the name of each resource caravan is given in brackets beside the resource caravan circle.

The framework shows six mothers linking resource caravan 1 to an empowering resource passageway. Four mothers linked resource caravan 2 and an empowering resource passageway. Three mothers linked resource caravan 2 and an opening resource passageway. These links suggest that mothers with stronger resource caravans have more positive empowering and opening resource passageways. Conversely, the restricting resource passageway was predominantly linked to the more challenged resource caravans 4 and 5, and the limiting resource passageway was associated with resource caravans 3 and 5, which suggests that mothers with limited and restricted life courses also had less effective current resource reservoirs.

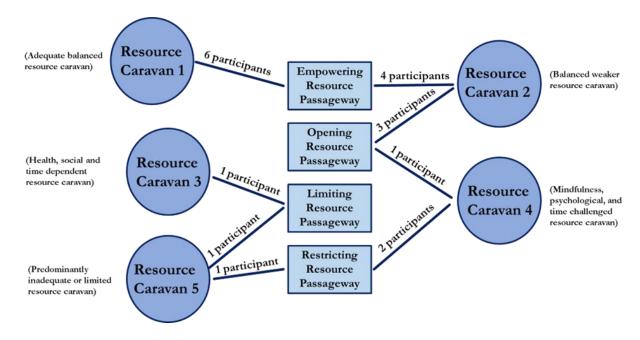


Figure 4-5: Framework of resource passageways and caravan associations (author devised)

It should be noted that more mothers were clustered within resource caravans 1 and 2, and relatively fewer in resource caravans 4 and 5, which inevitably influenced the numbers connecting the resource caravans and resource passageways in the framework.

Links to regulatory mode

I next sought to establish whether the associations between resource passageways and resource caravans could be linked to regulatory mode orientations.

Earlier in this chapter I determined an association between a well-resourced resource caravan and a locomotion orientation. My earlier analysis identified a connection between enabling and opening resource passageways and the better-resourced caravans 1 and 2. My analysis also therefore identifies a relationship between these resource passageways and locomotion orientation. Moreover, earlier findings also suggests an association between a mixed regulatory mode and a poorly resourced caravan. Although there were only three mothers to suggest the latter association, the analysis also suggests a link between limiting and restricting resource passageways and a mixed assessment and locomotion orientation. These relationships are summarised in Figure 4-6, which shows a higher locomotion orientation associated with resource caravans 1 and 2 and a mixed assessor and locomotion orientation associated with resource caravans 4 and 5.

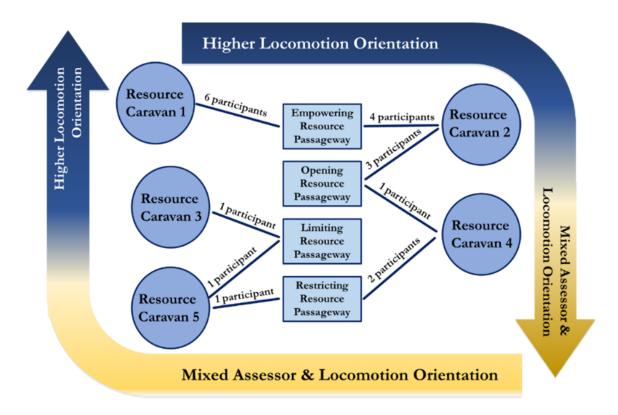


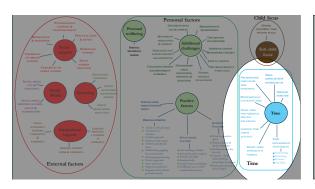
Figure 4-6: Framework of resource passageways, resource caravans, and regulatory mode associations (author devised)

As my earlier findings failed to identify an association between a resource caravan type and assessor orientation, an association between assessor orientation and any of the resource passageways identified cannot be concluded.

This chapter now considers the roles of time and social support for mothers caring for neurodivergent children.

Figure 4-7shows a highlighted snapshot of the thematic map set out in

Figure 3-10, and Excel table (Figure 3-13). It spotlights the concepts and themes derived from my interviews with the mother's that were used in this section of the findings to understand the roles of time and social support for mothers caring for neurodivergent children.



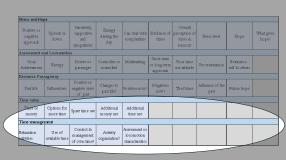


Figure 4-7: Highlight of concepts and themes used to understand the roles of time and social support for mothers caring for neurodivergent children.

Time sub-themes

<u>Sub -Theme 1</u>: Time is limited, so needs controlled use.

<u>Sub-Theme 2</u>: Need time for mental wellbeing.

<u>Sub-Theme 3</u>: Neurodiverse care can be time consuming.

Sub-Theme 4: Multitasking.

<u>Sub-Theme 5</u>: Prioritising.

<u>Sub-Theme 6</u>: Professional providers can waste carers time.

<u>Sub-Theme 7</u>: The need for more time.

<u>Sub-Theme 8</u>: Limited time limits activity.

Sub-Theme 9: Flexible use of time.

<u>Sub-Theme 10</u>: The use of routines.

<u>Sub-theme 11</u>: Short-term approach is normal

Figure 4-8: Time sub-themes (author devised)

The analysis of the data from the mother's revealed several sub-themes related to time, which are elaborated upon in the subsequent section but summarised in Figure 4-8. The sub-themes identified the mothers' perceptions, challenges, and approaches to time management. Mothers recognised the need to care for themselves as well as their children and explained the approaches adopted to achieve control. The order in which the

subthemes are covered reflects the significance of the themes rather than a more logical ordering of the issues followed by the solutions.

Time is limited, so needs controlled use.

A prominent subtheme of time was that mothers recognised that limited time necessitated efficient time use through planning, organisation, control and routines. Lexington explained how she maximised the hours available to her

"I also get up early, so I have lots of hours in the day, but yes, masses of planning. I've got a calendar where everything's written down. And I'm just looking ahead all the time, thinking okay, that's going to happen by Thursday or whatever. I just have to plan it all out" (Lexington).

Although mothers were generally adept at planning and prioritising, multiple demands created a sense of being overburdened, leading to discomfort

"I find that I can struggle to prioritise, and I feel constantly pulled in different directions, which makes me feel uncomfortable" (Eversen).

For some mothers, the level of burden could lead to feeling perpetually overwhelmed, despite using time management strategies

"... the lists became ineffective when I just couldn't get anywhere, because I couldn't pick the first thing off the list, let alone the other ten things off the list" (Landry).

There was acceptance of mother's capacity constraints and recognition of not being able to manage all their responsibilities

"[If I had more time] I would do things like tidy the garden, go to the tip, I would go clear out the loft, sort out things I never have the time to do, but I know need doing" (Lexington).

Feeling overburdened could distort work and home life boundaries and present difficulties in maintaining acceptable balance. Honor, with a full-time managerial role, spoke of her challenges balancing work and childcare

"I have too much work, not enough hours in the day, and it means I'm spending less time with the family and I'm not really liking that" (Honor).

Accepting personal limitations led mothers to distribute tasks among family members to reduce their burden to make it more manageable

"We do try to share the responsibilities, my husband can get flexible time at work and does come to meetings if both of being involved will be useful, and sometimes, because if we're both there, then we don't have to try and tell the other person what's happened" (Honor).

Faced with time challenges, mothers focused on more achievable tasks, prioritising goals that aligned with available time and resources, and consciously putting aside goals they perceived as too challenging within their time-constraints

"I'll look at it and think it needs doing, but I haven't got the time to do it, so I won't even start because I know I won't see it through, or get it done, I'll think there isn't time to do that. Yea, so not attempt it" (Callaway).

This pragmatism helped mothers focus on the goals that they felt they could achieve. However, it could result in feelings of poor commitment, as activities perceived to be important but challenging remain unaddressed. Mothers drew support from others to help them maintain commitments in their constant dance with time constraints

"But I'm also making the best use of the time I have, and I normally try to get someone to try and keep me to what I've committed to, because I know in the end that's good for me, and then when I'm there, normally it's great" (Luxor).

To manage their time efficiently, several mothers adopted a more holistic approach to navigating multiple demands; being more strategic and structured helped them manage competing demands

"Yeah, that's the only way it really works for me now. So, if there's gonna be any washing done, it's done on this day or at this time of the day. I'm allocating tasks to days or parts of days to make sure things get done" (Callaway).

Others segmented their days for work, household tasks, childcare, and personal pursuits

"But I literally go straight to work from dropping the kids at school, and that's my time to get myself into work mode. I don't take a lunch break, and I'll eat at my desk and leave to collect the kids in time to pick them up at 4:00 o'clock, and so as long as I'm in the car by quarter to four I'm Ok. I'm normally running from the car and running back to the car. And in the car to school is when I can go back into mum mode" (Honor).

Using techniques to organise their lives allowed mothers to reclaim control and foster healthier work and family balance. Mothers generally achieved this through detailed and consistent organisation of their time and practices that maximised their time-use

"I just have to schedule it all in, otherwise it all falls down" (Lexington).

Organising the use of scarce time through control and time management techniques stood out as crucial components in most mothers' daily routines

"I've got rotas, I've got lists and timetables on our wall, so everybody has a time where they make their lunch, time slots so they know which order to do it in and they're not allowed to start getting in each other's way" (Jupiter).

The use of routines was also frequently referenced for optimising time use and creating structure

'I more of squeeze things in when I can, but it has to have a certain predictable routine, because I can struggle to remember if it is too different' (Hollis).

Planning and coordination supported a perception of control in relatively chaotic lives

"But I like to do lists, well, I start to do lists, but I don't necessarily finish a To Do List, because I'll get distracted and find something else to do.... I'll get part way through and think, I'll have a cup of tea, and then oh, I might just do this or that" (Honor).

Routines could help work-life balance

"Then I leave work in time to pick them up, and they either get their homework done, or they may do a bit of play, or after school activities. I do dinner while trying to help them do their homework" (Honor).

This helped mothers manage their time

"So probably because of living with George, I have quite a strict routine and that helps with my time management" (Arden).

Finding an appropriate combination of approaches allows mothers to navigate their time limitations more effectively. Despite this, perceptions of chronic time scarcity and an inability to fully achieve necessary goals, often through a perceived lack of agency, could negatively affect mothers' feelings of control and self-efficacy

"I do get things done, but it's just that general awareness of sort of being in an environment where I would like to separate things out, but I can't. It's sort of just constantly needing to do little bits around the house, but actually needing really focus on things, but never having enough time to do everything" (Eversen).

The extent to which mothers were able to organise themselves and those around them appeared directly related to the control they had over their lives

"I try to just use my diary as a planning tool to be semi-organised. It doesn't always work, but you know, I feel if I feel I am organised then I feel I'm in control. If I'm not organised, then I'm not in control" (Ocean).

Some mothers attempted to regain control by being more directing, resolute, and honest, in their approach to others, whilst explicitly recognising their own limitations

"I used to be quite time conscious, and I think that having the boys, I found it all so stressful, watching the clock and not doing the things that I needed to do so now I just say, sorry I'm late" (Brighton).

Managing not only themselves but also those around them could lead to conflict as mothers became more forceful in their approach. Honor mentioned this in relation to her work

"My contract when I started last November was for 32 hours a week, but the job is so big and I ended up doing 40 hours, so I said right, you can pay me the extra to full-time because I'm doing it anyway" (Honor).

Mitigation of the negative impacts of time scarcity commonly resulted from these more assertive decisions and communication styles, including the confidence to decline requests or commitments

"I definitely take on lots of things, and that's been a learning curve, and I have had to learn to say no to people" (Brighton).

Need time for mental wellbeing

The second prominent time sub-theme was that mothers caring for neurodivergent children needed time to support their personal mental well-being to maintain resilience and well-being. There was a risk of maternal self-neglect in favour of neurodivergent children, as mothers frequently prioritised their neurodivergent children over themselves and everyone else

'I think that as a parent, you automatically put yourself at the bottom of the pile, and particularly as a mother And it's very easy to realise I've done absolutely nothing for myself. I mean, I recently joined a choir just to have something once a week that was for me, something that doesn't involve, is not about my children. -.... Yeah, it's just for me. And I think if you've got children with long term illnesses, somebody needs to be making you do that, especially if your life is busy and you've got other children" (Briar).

Landry reinforced the sentiment

"I still find it difficult to do that, it's like on an aeroplane where they tell you to put your own oxygen mask on before you put your kids' masks on. Well, metaphorically, I've never done that" (Landry).

The impact of this focus on their neurodivergent children could limit mothers' attention elsewhere, including effects on much-needed social and personal relationships

"And I know there's no way that I could if I'd been in a relationship, that I would have been able to devote myself in the way I have. That's why I'm not in a relationship, because the idea of having any extra time for anybody is just ridiculous. It just couldn't possibly ever work" (Lexington).

It could also negatively affect their close family, particularly much-needed spousal relationships, which could be sidelined in favour of neurodivergent children

"... we're having to rebuild our marriage because, you know, that's the last thing to have been given any time or energy to, that's just not been my priority, and that's been hard for James, you know" (Landry).

Although the focus on neurodivergent children appeared to have frequently negative outcomes, it could also benefit mother's well-being, as Cypress said

"You just wanna make sure your kids are happy, because when they're happy, then I feel happy, and life doesn't seem a problem" (Cypress).

However, the focus on the neurodivergent children could be extreme, leading to maternal blame, extreme-focus, and decreased self-care

"It's kind of the guilt all the time that stops me from doing a lot of things" (Luxor).

It could also lead to feelings of guilt about other family members who may lose out because of the mother's focus

"My [neurotypical] daughter is a really keen gymnast and people want to poach her for competitions, but I can't give her that support because of all the other needs that we've got to deal with. So, you know if she was an only child, she'd be, you know, she'd get a lot more support" (Brighton).

Access to supportive relationships can buffer individuals from the negative effects of stressors and enhance their sense of belonging. These key relationships were demonstrated with husbands, partners, parents (normally mothers), and close friends, whether through work or socially. The importance of husbands and partners was consistently noted

"... the one thing that probably could help us would be opportunities for us to have time together as a couple without the responsibility of being mum and dad on tap" (Ocean).

This was frequently associated with a need for closeness and empathy with someone they could relate to and share anxieties and concerns, but also for relaxation and normality, often with their children nearby

"You know, days are hard and busy and full on and fun but also tiring. And you know, I like the quiet evenings when everyone's gone to sleep and I'm just relaxing on the sofa with my husband" (Cypress).

Mothers also found solace and support from their family, frequently their mothers and siblings

"We'll see each other (her mother) regularly through the week, maybe five out of seven days. And she gives me emotional support too" (Callaway)

and

'I have a brother and sister, they live in London and we're close, as in, I can ask for support, or if we have an emergency situation, and I need them to maybe come down and step in, and they can, they will" (Eversen).

There was also reference to wider family support

"I've also got an aunt who calls me on the phone and that's really wonderful" (Hollis).

However, Hollis commented that support from close others could not be assumed

"All I want is someone I can empathise with, to say right, you know, I would feel the same. I have certain people that would say that to me, unlike my mum or sister who would just tell me I'm being unreasonable" (Hollis).

Outside the family, mothers valued practical help from close friends

"So, when I go up there, she makes a point of taking him out and giving me some time to myself" (Brighton).

Halston reinforced the value of support and understanding provided by a few close friends rather than many acquaintances

"I don't feel I've got very many close friends, but I've generally enough. Yeah, I'd say I have many acquaintances, you know, I know quite a few people, but I find I can't really count on them. It's a small group that you can actually rely on" (Halston).

But mothers frequently mentioned time constraints limiting meaningful contacts with close friends

"I struggle to meet up with friends because I have got a lovely lot of friends." (Cypress).

Perhaps consequently, several mothers developed important close friendships in the workplace, as Luxor said

"... and I can go into work and my colleagues get me and get my problems, and they can give me time and we can talk. And that helps me a lot" (Luxor).

Important for creating self-time for mental wellbeing, was the ability to acknowledge personal capacity limitations, which falls within the realm of self-regulation, enabling mothers to manage their stressors and emotional challenges more effectively

"But, you know, there's always something that needs to be doing, and usually, mentally, I'm quite drained" (Landry).

A key factor that mothers adjusted to accommodate time restrictions was their employment, which frequently affected their income and career paths

"I was working full-time for a healthcare provider. It wasn't a brilliant job, and it was stressful, but I was paid very well for it. But it was affecting my mental health along with the caring for my children, and it got to the point where if things had carried on, with all the assessments and things that we needed to do, I might have lost my job" (Luxor).

Many of my sample worked part-time, often adopting a freelance, 'gig' approach to create the flexibility they needed for childcare

"I work very part time, so I've got a zero-hour contract where I work and it's a sessional trainer job. I don't think I'd have the capacity to work full time or even part time. I couldn't do it. I wouldn't be able to manage all that" (Jupiter).

Mothers valued flexible working arrangements to help maintain much needed freedoms to balance work and home-life

"[Staring a new office-based job] ... I won't have that [freedom]. It's just gonna be in the car and get to work. So, I think that continuation of working from home, flexibility, hybrid working would be good to keep" (Brighton).

Many mothers accepted putting their careers on hold but continued to use and maintain skills through volunteering, which helped them feel more valued and useful

"I'll have really good ideas about things that I want to do, but I put them on hold because I just don't have capacity to even consider them. But I'm going to be on the preschool committee and help with their SEND [special education needs] stuff for the other children that come in September. Doing things like that, I feel like I can be useful, and the same for some church stuff" (Jupiter).

Although considerably burdened, mothers still appreciated the value of relaxation in creating a balance in their lives and supporting their well-being. Mothers found ways to relax, inevitably whilst also addressing their children's needs

"But with [if I had] an unexpected day off, I would come back, have a coffee, put something on the TV in the background, read a book. Time goes really quick, and by 2:00 o'clock, I need to walk the dog again because I need to do the school run for 3:00 o'clock. And then once the boys

are back, they're not gonna wanna walk the dog. So, I'd walk the dog again. Go get the boys. Then we'll do dinner. Clubs, get [them] ready for bed, yeah" (Cypress).

This notion of creating normalcy also extends to the workplace, which Brighton explained, can help with life-balance by creating a break from her routine child focus

"I think having my job being separated and having that time to myself gives me a good life balance" (Brighton).

However, the counter to needing occasional time away from the demands of neurodivergent children was the constant desire to care for their children, so they could bond with, support, and simply give their children personal attention

".... I got like put aside a lot as a child. So, I think I've tried to do the exact opposite, and I maybe overcompensate for that with my kids. And that's why I like having the extra time with them" (Brighton).

The key requirements of suitable employment were flexibility, manageable hours, and an adequate salary, as this allowed freedom to dedicate time to themselves, children, close family, and social networks

"You know, I've got all this time to be home and see my husband and the kids. So yeah, there's a lot of benefits to doing what I do" (Cypress).

However, appropriate employment normally necessitates a lower income

"I just think I'd be on my knees and just, money isn't everything. I do need to be at home and having some respite and time off as well, yeah" (Cypress).

Neurodiverse care can be time consuming

The third dominant sub-theme of time was that caring for neurodivergent children was significantly more time-consuming than caring for neurotypical children, whose reliance on parental support leaves little additional time for their mothers

"I think I probably spent 60% of my time on sort of PA [personal assistance] type duties for their needs" (Landry).

Demands included support with children's morning routines

'I will sort of prompt her and hand things to her like items and then hand her clothing the right way around so that she's holding them and then she can make an attempt to put them on" (Callaway).

and frequently extended to the school environment

"They don't like walking into a full room of people, so I help them settle in school with the teacher. ... And then I take my youngest on to preschool in the same village. ... She has a very specific routine of what she does when she does it, how she does it, but if somebody interrupts that flow, she won't settle. I'm often there till about 9:30 in the morning trying to get her through the door. So, I can be quite weary when I get home" (Jupiter).

Parents often mentioned that dealing with external agencies, specifically the education system, local authorities, and community adult and mental health services (CAMHS), could be complex, time-consuming, and stressful. The system reportedly lacked coordination, flexibility, and empathy for the challenges faced by parents

"So, a lot of the complex issues that we're dealing with have no resolution. So, things like how to access social care that's going to meet George's needs. There isn't any and we spend a lot of time thinking about innovative solutions" (Arden).

Mothers felt formal support agencies had little consideration for carers or children's needs, captured by Landry

"So, it's just the exhaustion from constantly having to fight, and it permeates itself not only into the outside world, but you, and you're constantly in this fight mode all the time" (Landry).

Parental advocacy for their neurodivergent children could absorb caregivers limited time

"So, a lot of my time is taken up fighting for them and being their advocate, going in and saying that he or she not coping with something, and please could we try this, and I spend a lot of time in school" (Jupiter).

Completing extensive paperwork on the child's behalf exhausted mother's time

"... and I'll be up till 10:00 O'clock on a Friday night and spend three hours filling out EHCP application forms, or things like the DLA forms you have to do. The DLA is a 48-page document about your child's needs, and I've had to do five of those, plus all the renewals, plus the PIP one. There's a lot all the time" (Jupiter).

Where support from agencies was provided, the time burden could still be onerous and draining

"We have core meetings every month and there are panel meetings, to sort of, look into all the issues we're having with my son. So that takes up a lot of my time and affects me emotionally as well" (Callaway).

Non-specialist schools were frequently criticised by mothers for the teachers limited understanding of neurodivergence, being unsupportive and unhelpful, and requiring daytime inputs from the mothers

"[her son was fouling himself at school] I said can someone not pre-empt it and just say Alan, go and go to the toilet before you go out to play. They just said they didn't have time for that, so and I said right, I'm gonna come into school and take him to the toilet before he gets out to play" (Ocean).

Parents complemented the understanding and approach taken by specialist schools, but even this could be at the expense of the mother's time

"... there's a lot of interaction with school, which is good. But it all takes up a lot of my time and for example, I have a meeting this afternoon for an hour at school. There's a meeting every half term, but that's brilliant, because they involve me so well with his plans, and what they think will be good ideas for him. They routinely check-in with me, which I think is fantastic, and it's really reaping rewards, but it all takes ... time" (Lexington).

Arranging childcare during school holidays could be challenging for all parents; however, the challenges could be particularly significant for parents with neurodivergent children who often also had associated disabilities

"That is always a total, utter nightmare, and I'm spending hours trying .to sort that out because Riley's special needs are such that he can't do mainstream childcare, but the special needs provision is usually inappropriate for him as well" (Lexington).

Time management techniques

As noted, the key techniques used by mothers to manage time challenges were multitasking, prioritising, and adopting a more flexible and short-term approach.

The volume and range of tasks tackled by mothers brought inevitable challenges as mothers balanced childcare with the multitude of other life factors

"But then, as I say, them days where I've got the kids 9 to 10 days in a row and I'm trying to juggle work activities, school holidays and clubs and try to get everybody everywhere, I wonder" (Brighton).

Mothers commonly acknowledged the limitations of their capacity

"Lots of things all at the same time, usually half done" (Arden).

The range of tasks meant that multitasking was essential

"But then I get on with the housework and usually I have meetings, and I've got paperwork to do, forms to fill out or emails to chase people on. Then I'll probably get on with work. I'm planning training sessions, and there's always something I'm meant to be doing really" (Jupiter).

Prioritisation was a necessity in the mothers' busy lives

"Lots [to do] at the same time I guess, but I prioritise. I can do important things first, but I might have a lot of things in my head that I need to get done" (Cypress).

Mothers prioritised self-care, work, households, children, immediate families, and a wider family. They also needed to prioritise the use of their limited income for optimal effect

"I pace myself because I get a bit stressed if I take on too much and I don't like overcommitting, but at the same time I like to be busy and doing things. So, I have to balance out what I'm capable of and what I can deliver on" (Eversen).

Prioritisation came with sacrifices. Landry used the analogy of a needs hierarchy to explain this

"You've only got a certain amount of energy, and you have to direct your attention to the things that you want to prioritise. But now I don't have those priorities, you know, I can work at a lower level, it's kind of like Maslow's hierarchy of needs" (Landry).

Perhaps inevitably, implementing this hierarchy in a family environment could bring about relationship challenges

"We've had to forgo a lot, you know, we're having to rebuild our marriage because, you know, that's the last thing to have been given any time or energy to, that's just not been my priority, and that's been hard for James, you know" (Landry).

The challenges of prioritisation could be particularly relevant as mothers switch attention between their children

"And it's so hard to focus positively on the good one, because then you get the jealousy from the ADHD child. You know, you don't take me out to the cinema, or you don't do this with me" (Cypress).

It applied similarly to the wider family

"... and if dad becomes unwell, then I can run down in the car to him and see them. I can juggle my shifts because I only do two nights a week, so I can get back to Dorset for a few days. But Monarch's my main focus" (Cypress).

Mothers were adept at using approaches that maximised time flexibility within their family routines

"So we both do the school run, but that's because my husband's job is flexible, and he can afford the time to do that. And then he comes back and works after that, or he'll book meetings around the school run" (Jupiter),

or through coordination with their work

'I'm going to ask my employers If I can work 8:30 to 4:30. I think they will agree. I'll just need to make up any time I miss in the evening and at weekends" (Lexington).

Flexibility required parents to make sacrifices, not least with their careers if they were to achieve the capacity they need to care for their neurodiverse children

"I do freelance work. I work for a couple of different organizations, and there's also always a huge amount of paperwork to do around my eldest son, so I would use that time if he's not awake to catch up on background work. I have to be very responsive so that if I'm taking my son out to an appointment or if he's got a sudden need for me to spend more time with him or to sort out a difficult moment that he's going through, then I can do that" (Eversen).

Ultimately, mothers took a short-term approach to what they did, and more proximal task solutions were sought

"Firefighting. Whatever's on fire, that's what gets my attention" (Arden).

However, a short-term focus with a lack of broader awareness could narrow parents' focus

'I just took a long time to accept there was a real problem, and more so for my husband, because Monarch could be good and could do good behaviour. But then there were times also when he was very, I guess, well, very naughty and really way beyond what a normal child would do' (Cypress).

The need to address current issues could also risk parental wellbeing and with it, hope

"Yea, I get stuff done, but I struggle with the future, and I worry all the time about that"
(Brighton).

These sub-themes collectively illustrate the complex relationship that mothers have with time, balancing responsibilities, priorities, and personal well-being. In summary, the key subthemes related to time centre on the additional focus required to care for neurodivergent children. This includes the time required to deal with formal support agencies, whether directly or through onerous levels of paperwork, and the processes involved. Mothers used techniques to organise, plan, and control their time use. These techniques include multitasking, prioritising, routines, flexibility, and generally, a short-term approach to task management. Adopting these techniques does not eliminate the burden or discomfort that they experience. This frequently results in a sense of poor control, self-efficacy, and greater negativity about the future. The value of social support in providing practical support, advice, and solace was evident in statements made by the mothers. This will be explored in the next section.

Social Support

The following section describes my analysis of the mothers' comments on their social networks.

The mothers' social networks were diverse, with associations inside and outside immediate families. Important networks included the wider family, friends, church, voluntary organisations, other mothers, professionals, and links made in or through the workplace. Quotes demonstrate how mothers appreciated empathy, acceptance, and emotional support from their social networks.

A snapshot of the thematic map in Figure 3-10

Figure 3-10

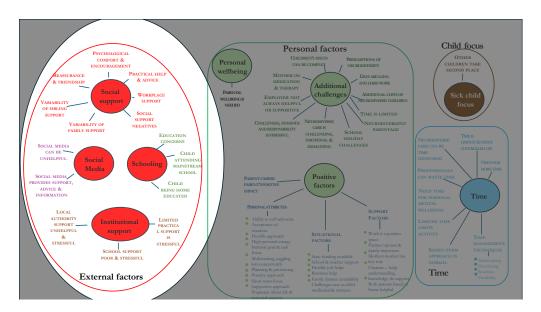


Figure 4-9: Themes within the thematic map addressing the role and importance of social support

Networks provide opportunities to discuss struggles and seek comfort in a safe environment through shared experiences and empathy. Furthermore, mothers valued the guidance and knowledge they shared within these networks. These factors add to their resilience and sense of empowerment in handling their children's unique needs. The subthemes are summarised in Figure 4-10.

<u>Sub -Theme 1</u>: Psychological comfort and encouragement.

<u>Sub-Theme 2</u>: The variability of family support.

<u>Sub-Theme 3</u>: The variability of sibling support.

<u>Sub-Theme 4</u>: Reassurance and friendship.

<u>Sub-Theme 5</u>: Practical help, and advice.

Sub-Theme 6: Workplace support.

<u>Sub-Theme 7</u>: The negatives associated with social support.

Figure 4-10: Social Support sub-themes (author devised)

Psychological comfort and encouragement

Mothers reported gaining psychological comfort and encouragement from their social support networks, and an important element of this was emotional support and understanding, whether in person or remotely

"I'll have a chat to best friends and maybe text message too. If I've had a bad day, I'll just ping the message over to somebody" (Brighton).

This support provided opportunities for sharing experiences, feelings, and challenges. It also reassured them that others lived lives related to their own. Mothers placed significant value on social networks

"I think it's that you're not that lone lighthouse, and there are other people that are going through the same thing. Maybe not the same time, but they completely understand the predicament you're in and you can sort of share stories, or they can offer some guidance and things that have worked for them, or just to be there for you. You know, they get it. They completely understand where you are, and you can offer each other insights from what you've been through, or you know" (Landry).

The mothers commented on the value of exchanging information and practical advice within their networks. This helped them navigate the challenges related to their children's neurodivergence. Mothers found the reciprocal exchange of knowledge and information valuable. This includes practical advice, strategies, and insights related to parenting neurodivergent children. Arden mentioned that conversations with other mothers allowed her to learn about different approaches and solutions to common issues

"... so it's emotional support, but also knowledge. Information sharing. So, there's a few mums ... I saw one yesterday who I've known a long time but would only see them once or twice a year in passing, but [as soon we] see each other, it's like, you know, straight in, in the weeds. What are you doing about this? What you're doing about that?" (Arden).

Mothers found solace from being acknowledged and listened to

"It's all about being heard, really" (Ocean).

It was also about being accepted, and having someone they could relate to, trust, and draw from within their social circles, particularly when discussing their children's behaviours or challenges and their own feelings and concerns

"Sometimes you feel so understood that you don't have to say anything, you know, it's that sort of relationship, really beneficial and protective" (Luxor).

Sharing experiences of parenting neurodivergent children created bonds among mothers who valued opportunities to connect with others who truly understood their predicaments

"... we get together once a week for a dog walk and a moan and we walk the same walk, have a coffee, go through all five children. And she's got adopted boys who've all got additional needs. And our kids grow up together. So yeah, we've got a lot of common experience" (Arden).

Peer support was also valuable for validating mothers' experiences and emotions, especially when encountering judgmental attitudes or misunderstandings

"Whereas when you do find your tribe, they're, well everything, is much more accepting and understanding. You get some of the sort of really judgmental people, like, massively judgmental and who won't do anything for anybody, regardless of whether we know them or not, so I just prefer to focus on the nice people rather than the judgy ones" (Clover).

Variability of family support

Another common sub-theme was that wider family support varied and could not be assumed. Mothers perceived a lack of practical support from their extended families, and challenges gaining assistance with their childcare, or understanding of their children's neurodivergent condition and needs

"Support has been really difficult since moving up here because everyone is [a few hundred miles away], both our families. So, to be honest, I don't think we do have any real family support, it's just me and my husband." "My mum and Dad are very supportive, and they will always listen to me, but I don't think they understand ADHD and Monarch's behaviour. I mean, we were brought-up with a smack bottom, and you know, you need to be quiet children, and you know, to listen to adults" (Cypress).

Some mothers described strained relationships with family members, including parents, siblings, and in-laws, often due to limited understanding of, and support for, their parenting challenges

"I think my husband's mum and dad find it really hard to understand my eldest, so they don't look after him. ... But my step mum used to [work in mental health care], so she understands him, and she's sort of forced my dad to understand him more. But my dad will still think why can't you just make him go to school?" (Kingsley).

These barriers can inevitably affect family relationships

"I sometimes think she just thinks I'm making it all up. It's the same with my siblings, and I wish I had a closer relationship with them" (Hollis).

This resulted in mothers relying heavily on their spouses for emotional and practical support, highlighting their pivotal role for navigating the challenges of raising neurodivergent children

"It's just me and my husband" (Halston).

Frequently, although not consistently reported, was the comfort that mothers found in their close relationships with wider family members. This was particularly true for parents, particularly for mothers. Practical assistance was invariably limited, but emotional comfort and reassurance were common

"... so if I'm upset about something, I'll just call my mum and [she] did sort of fill that role, reassurance function. But they're getting older, and I don't want to say they're getting less useful, but the practicality stuff is getting less there because they can't support in that way now. It doesn't mean I won't call them and talk through it with them, but I'll ask them even though their advice

now is less practically kind of actionable, but not always. They're still there for, like, love and support" (Halston).

Despite understanding the limitations faced by their parents, many mothers expressed a desire for greater support and understanding from extended family members, particularly regarding their children's neurodivergent needs

'Like we've said, really, I'd like more support from the children's grandparents. I'd like them to be a bit more involved, but I do also understand that they don't have to be any more involved' (Cypress).

Variability of sibling support

Many mothers also expressed a lack of support or recounted their strained relationships with their siblings. Some described disagreements regarding fundamental issues, feelings of frustration or anger, or a general lack of effort from siblings to maintain a close relationship

"And I have a brother, but we're not close. So, he's not somebody that really I could use as a support because we disagree fundamentally on some of the fundamentals of life" (Briar).

Some mothers emphasised the emotional impact of their family dynamics, including experiences of emotional abuse, controlling behaviour, and feelings of exclusion or alienation within their family relationships. These life-course events in their past, affecting their current lives

"Well, my brothers as well, but not necessarily in a positive way. So, they're like five and six years older, and they were quite bullying to me, and thinking back, I think that did shape a lot of who I am now. Quite a lot, yeah, kind of with a lot of things, you know, I sort of think twice about doing things, it damps down my enthusiasm now" (Callaway).

Although there were frequent mentions of unhelpful relationships with siblings, mothers revealed positive relationships with other family members such as cousins, uncles, and aunts. These often involved emotional and occasionally practical support, creating a sense of connection and assistance within family networks

"He [her son] generally tries to phone my uncle for an hour, and they speak about maths, it's like babysitting remotely, because he just sits at his desk and speaks to my uncle on the phone" (Hollis).

Reassurance and friendship

Reassurances through acquaintances constitute another significant subtheme of social support. Mothers found reassurance in not just their friends, but also neighbours, and local communities where networks of contacts were formed

"And with the small community, come networks Obviously, you can use your own networks, but you can also then tap into other people's networks and that's really powerful and useful" (Arden).

Mothers emphasised the value of these communities within their social networks, which offered understanding, assistance, and belonging. Ocean referred to the neighbours in her apartment building

"Our stair was practically like a little family, helping and supporting each other... It's a nice balance between nosey and helpful" (Ocean).

Diverse support systems are formed by friends, family members, church communities, and peer groups. Mothers valued support from a few, rather than many people within their networks, seeking support from different elements to meet their varying needs and challenges

"So, I have my friends, but I think it's best not to have too many... I kind of have my different friends for different things" (Honor).

Mothers expressed the importance of finding acceptance and understanding through people who shared similar experiences and could offer important non-judgmental support

"I think my children's friends are like support network in themselves. My children's friends have a lot of understanding about my children, like they are part of us, like their parents are too because they see a lot of us" (Brighton).

Practical help, and advice

Analysis of the data identified the importance that mothers attached to practical advice and support from others with similar experiences or expertise. They gained this face-to-face, through online resources and professional networks to help them understand their children's conditions and access relevant information

"I just want to find out as much as I possibly can, and I try and speak to other people who've got the condition or other caregivers and just try and tap into all sources of information that I can"

and

"Peer support is a massive thing for me... And when he got [his] diagnosis, I was straight on the Internet trying to find out as much as I could" (Ocean).

Mothers emphasised the importance of having someone to talk to and share their experiences with, highlighting the emotional support and understanding they received from peer-parents facing similar challenges

"Sometimes just talking about things reminds me of how helpful something was. Having someone to talk to, to try and get down to the cause of the problem has been like my biggest asset" (Brighton).

Mothers emphasised the value of building trusted relationships with friendship groups as well as with professionals who provided practical help, advice, and guidance during challenging and uncertain periods

"One of the parents is also a SENCO [Special Needs Coordinator] at a school, and she talks to me and tries to help me. So, I just feel really fortunate having such a helpful, understanding bunch of people that we spend a lot of time with" (Kingsley).

However, mothers also benefited from practical assistance from their social groups

"I've got such a good group of friends that if I said to them, I have to get away for a week or I really need you to come down or something, I think they would ..." (Landry).

Workplace support

My findings revealed the importance of the workplace for social support. Mothers highlighted the significance of a supportive work environment in which colleagues understood their challenges and provided emotional support, fellowship and solidarity

'I can go into work and my colleagues get me and get my problems, and they can give me time and we can talk. And that helps me a lot" (Luxor).

Mothers also viewed their workplaces as social spaces where they could interact with adults, form connections, and receive support from colleagues, thereby contributing to their overall well-being

"I've got the people I work with for wider support. And because my work supports people with additional needs and disabilities, they've all been through very similar things to me and there's always somebody I could talk to if I had a specific issue and how I should go about it" (Jupiter).

Mothers valued the relationships they had with work colleagues, viewing them as supportive, providing practical assistance, understanding, and empathy when it was needed

"Other positive people, my current boss is a bit of a hero of mine... He's not very good at saying well done... But the support is always there for me" (Merritt).

Several mothers emphasised how their work environments provided them with emotional respite and support, allowing them moments of reprieve from their home lives', and opportunities to discuss their challenges with understanding colleagues or supervisors

"I've a very understanding boss who will quite happily listen to me going on about things and why everything is so stressful for me. Yea, half an hour of this happened and then this happened, then half an hour of work chat. That really does make a huge difference for me" (Clover).

The negatives associated with social support

Negative associations with social support networks were also observed. Some mothers expressed feelings of isolation or disconnection from their friends and other parents. This was often due to the unique challenges that they faced with their neurodivergent children. They expressed challenges relating to, or engaging with parents whose children did not share similar neurodivergent conditions

"The other day at rugby, some parents were comparing notes about like, how their kids were lacking independence and not doing things for themselves. I just sat there, and I didn't say anything, but I thought, wow, you really have nothing to worry about there, but I couldn't say anything, because it would've just brought everyone down" (Kit).

Mothers mentioned a narrowing of their social networks because friendships failed or became strained through the unique demands and challenges of parenting neurodivergent children

"... when you have neurodiverse children, all your friends' become parents of neurodiverse children, and you lose any other friendships that you have" (Landry).

More positively, several mothers reported finding organised parental support valuable, specifically those tailored to the needs of parents with neurodivergent children but also expressed frustration or disappointment with the lack of accessible options. Although difficult to access, these groups provided valued opportunities for face-to-face interaction and support

"Is there no parents support group that actually meets anywhere? I haven't found one" (Cypress).

Overall, the sub-themes underscore the challenges and complexities of forming, maintaining, and exploiting social networks among mothers of neurodivergent children. They highlight the value of support for caregiving responsibilities in familial relationships. They underscored the importance of supportive work environments and work colleagues in providing social connections for emotional support and respite.

The aim of this study was to explore opportunities to develop practical interventions to enhance parental resilience and coping mechanisms to support mothers caring for neurodivergent children. This final section identifies the competencies, capacities, and skills needed by mothers and identify potential interventions and approaches. Figure 4-11 shows a highlighted snapshot of the thematic map set out in

Figure 3-10. It spotlights the concepts and themes derived from my interviews with the mother's that were used in this section of the findings to consider practical interventions and approaches that can be identified for mothers caring for children with neurodivergent conditions to support their resilience and enhance their coping capacity.

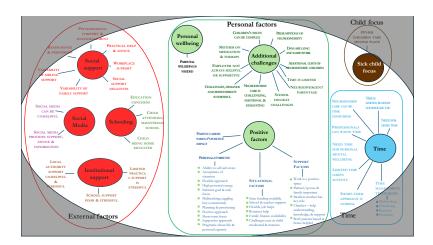


Figure 4-11: Highlight of concepts and themes used to provide practical interventions and approaches that can be identified for mothers caring for children with neurodivergent conditions to support their resilience and enhance their coping capacity.

The preceding sections help determine practical interventions and approaches that can be identified for mothers caring for children with neurodivergent conditions to support their resilience and enhance their coping capacity. Earlier findings identified nine key resources for mothers and clustered them into five resource caravans. The most challenging resources for mothers emerged as mindfulness, psychological and social support, and personal skills. Social connections, the importance of time, and social support were emphasised earlier in this chapter. highlighting the key resilience factors for mothers. They emphasised the importance of diverse skills, specifically emotional regulation, time management, social connection, compassion, knowledge, understanding, and assessment.

Further analysis of the data stressed four essential capabilities and capacities required for mothers caring for neurodivergent children, namely mindfulness, time, knowledge, and compassion (self-compassion and compassion for others). These capabilities and capacities largely reflected the most challenging resources for the sample. These included mindfulness, psychological challenges, social support, and personal skills.

Supporting the four key capabilities and capacities emerged as the overriding intervention needs that require support. They, in turn, enable capacity for six broader skills which emerged from my analysis as being particularly valuable for mothers. These six skills were time management, coping, emotional regulation, compassion, knowledge, understanding and assessment, and social and connection skills. The six broader skills support the achievement of goals or outcomes needed by mothers during the progress of the neurodivergent child's journey. The goals or outcomes needed by mothers were resilience in caring, parenting, self-care, living in the present, adapting, and embracing the future through learning, development, progress, and hope. These goal achievements are facilitated by mothers' collective skills. Key influences on the mothers were also noted. These include social connections, child condition and behaviours, family function, support, time availability, life situation and management, institutional involvement and interaction, and mothers' functioning and health.

In the following section, references will be made to some existing quotes rather than repeating them; some quotes are therefore referenced through underlined hyper-links to the original data. For hard-copy references, page numbers or an appendix are also included. Where appropriate, quotes are included to reinforce key elements of the model.

At the heart of the proposal is the mother, who has multiple challenging roles, partly captured in the following comment

"It can feel a little bit like you're running on empty sometimes. ... I think there's a knock-on effect of working as well, trying to juggle everything. Being a parent, a wife, a carer, you know" (Bellamy).

In my sample, the mothers were the key carers for both their neurodivergent and nonneurodivergent children, although the neurodivergent children were the common focus

"... actually Josh [her neurotypical child] gets left a lot and ignored, and he's quite good at playing on his own. And our focus is so often on Monarch [neurodivergent child]" (Cypress).

The mothers were frequently key wage-earners

"I was so stressed [with her caring responsibilities], thinking, I'm just going to have to leave [her job], and I'll have no income. I was saying to my work I won't be able to pay my bills" (Kingsley),

frequently also running the household

"I am the workforce in the household at the moment and juggling all the balls" (Ocean),

whilst caring for aging parents

"My husband and I are also carers for his father who lives 10-to-15-minute drive away" (Merritt),

and maintained significant social networks

".... but our friends have kind of run with us. So, we have quite an understanding network, which I think is really helpful" (Brighton).

Time, social capacity, and the ability to find empathy and sympathy for their children, as well as a range of other people, were key resources for caregiver mothers. The mothers demonstrated great sympathy for their children to accommodate their sometimes-extreme

quotes. They accepted practical coping approaches, including the accommodation of the needs and demands of their neurodivergent children

"I don't know if it gives him [son] something else to concentrate on, but if he brings me his clothes and I iron them he's more likely to be more comfortable with them than if he's putting them on straight from the box their clothes are in" (Brighton).

Mothers mentioned avoiding conflict which could be personally challenging, requiring significant cognitive-coping strategies

She [daughter] is so controlling of me, it's like I'm her remote control" (Jupiter).

However, the mothers also needed to care for themselves and deal with their own distress, and this routinely depleted their emotional resources

"Time to myself as well, to regenerate, yeah" (Bellamy).

The need to identify self-time and self-compassion from personal resources that are constantly stretched and frequently exhausted was summarised by Clover

'It's highly stressful, and it's constant, it's 24/7 and then, it's the mental load. It's just always there, and because I'm aware of the stress, I make more of an effort to make sure I get time to myself. I'm much better able to cope with it if I've had a bit of exercise first thing in the morning, it sort of sets me up right for the day and all that, right? I can cope with the world then" (Clover).

Resilience, personal progression, learning from adversity, and capacity to deal with distress from factors within and outside the family were essential. Stressors associated with neurodivergent childcare appeared continuous

"But the worry and the pressure and responsibility never actually goes away" (Bellamy).

Positive outcomes for parenting and self-care were obtained in the face of distress. Data suggested these were centred on supporting caregivers' well-being, improving their knowledge and understanding, and helping them develop effective approaches for managing time.

Comments by the mothers identified mindfulness as significantly important for support in managing their anxiety, distress, and well-being and to help them interact with their children and others. Compassion, both for oneself and others, was recognised by the mothers as another important capacity to help them accept their capacities, limitations, fallibilities, and responsibilities. Relational compassion for others beyond children and spouses, such as wider family and social networks, increased mothers' awareness as well as practical and informational support. It also appeared to support empathy for and from others while reducing stigma and potential social isolation. Time and its effective management emerged as a third key capacity to help mothers handle their diverse demands and utilise necessary skills to care for themselves and others who depend on them. Knowledge was a fourth key capacity or capability noted from the data.

Mothers' proficiency in mindfulness, compassion, and time management appeared to be closely tied to their skills. Skills noted included emotional regulation, time management, coping, compassion, social connection, knowledge, understanding, and assessment skills. These are discussed in the following sections.

Emotional regulation was essential for the challenged mothers in my sample, who routinely struggled with multiple demands, their children's challenging behaviours, and needs. These could chronically diminish their resource base

"Stressful and tiring. The lack of time, there isn't enough time to do everything that I need to do in the day" (Bellamy).

Negative emotions were noted from perceived lack of support, affiliate stigma, and frequent challenges in dealing with various support agencies.

'I was phoning the GP, but he couldn't help because we needed to go to CAHMS. CAMHS have a four-year waiting list, but the school are saying Monarch's behaviour is bad, and we just stuck in this cycle. (Cypress)

'I think something else that really gets to me, and of course every parent worries about their children, but if you sit around parents with regular children and listening, you overhear conversations of the

regular children and their problems, I just think oh my God, I wish I could say this was a problem for me. (Kit)

The resource of time was consistently limited for the mothers, and its use needed to be controlled and managed. This helped create time for themselves, their children, friends, and family; for employment and income generation; running their home; and arbitrating on their children's behalf. Time management was achieved through techniques such as multitasking, prioritisation, routines, flexibility, and short-term approaches to goals and tasks. Bellamy refers to limited time being stressful and tiring

"Stressful and tiring. The lack of time, there isn't enough time to do everything that I need to do in the day" (Bellamy).

The parents in the sample exhibited different coping skills and varied in their ability to handle challenges, distress, and stressors. This variability was partly influenced by stress appraisal and emotional regulation skills. These skills were shaped by their knowledge, understanding, and interpretation of their own situation, their children's situation, their capacity to make sense of what was happening, and their social support systems. These points are demonstrated in a comment by Eversen and in contrary comments by Lexington and Merritt in Appendix M.

Mothers' capacity for compassion varied, but most mothers focused on their neurodivergent children to respond to their needs, behaviours, or suffering. This could leave mothers struggling to find the capacity for compassion for themselves and others.

Self-compassion promotes empathy, generosity, and acknowledgement of one's circumstances, which can enhance one's well-being and adaptability. It involves accepting the need for self-care and compassion during challenging times and seeking support from others when necessary. Honour describes accepting help from others as having a crutch to lean on

And so, it's communicating with other people and just having a crutch to lean on, and you know, that really helps. (Honor)

Clover mentions her understanding of her strengths and skills while accepting her need to battle against the system

I seem to have been quite successful managing us to where we need to be. It all just takes so much longer, and I put the success down to my academic ability to look at the problem analytically. You know, this is what I need to do to solve the problem, and then having the writing skills to be able to put that down in writing and communicate effectively'. (Clover)

Landry explained her <u>increasingly positive mindset (p. 124)</u> through the acceptance of her situation and the identification of. positives, which could be used to enrich her challenging life.

Compassion enhances social bonds through increased capacity for connection. This provided mothers with psychological comfort, encouragement, practical support, and friendships, as demonstrated here

"[participant has an] Extensive support network, friends, face to face and online, weekly, and church, I would go to church at least three out of four weekends in a month". (Callaway)

However, compassion was a limited resource for the mothers. This could restrict their ability to connect with others. These effects harmed familial and social relationships, decreased social connections, and limited access to advice and support. Ultimately, this resulted in diminished or lost social networks, as demonstrated in the quote from Merritt

"[The] Local community doesn't exist [for her or her family]. And also, Polly's anxiety won't allow her[daughter] to socialise really". (Merritt)

Social support can act as an important buffer against stressors and poor health outcomes. The capacity to seek and accept social support is important for mothers caring for their neurodivergent children.

Although the children's neurodivergent conditions, behaviours, and progress were crucial to the mothers' resilience, their ability to respond positively was a dynamic process influenced by many factors. These included their life course, family, community, and level of stress or support they received from these sources. Cypress and Jupiter refer to

empowering resource passageways, demonstrating the importance of social connections and connectedness

"When I'm at work, I'm with my friends, they're nice people to talk to. I get a buzz from my job which is looking after people and feel really appreciated and important, and I feel my role's important, so that's a bit of a high for me". (Cypress)

My husband's family are also close family, his mum and his twin brother and his sister. (Jupiter)

They can include and embrace not only the immediate family as a supportive functional unit but also their wider family, friends, other parents, and work colleagues.

Occasionally, the agencies that supported the parent caregivers were acknowledged for their support and assistance. More commonly, comments have demonstrated that the agencies have added to the mothers' challenges and distress. This is shown in statements by Jupiter, Callaway discussing challenges regarding time

"So, it's just the exhaustion from constantly having to fight, and it permeates itself not only into the outside world, but you, and you're constantly in this fight mode all the time" (Landry).

"So, a lot of my time is taken up fighting for them and being their advocate, going in and saying that he or she not coping with something, and please could we try this, and I spend a lot of time in school" (Jupiter).

Where support from agencies was provided, the time burden could still be onerous and draining

"We have core meetings every month and there are panel meetings, to sort of, look into all the issues we're having with my son. So that takes up a lot of my time and affects me emotionally as well" (Callaway).

and anxiety are associated with the internal states of parent caregivers and a range of external influences. This necessitates consideration of the individual within their family, social context, and wider ecology. <u>Comments from Jupiter, Cypress, Eversen, and Landry</u> on P.151-152, discussing time management, supported this.

Mothers generally struggled with conflicting advice, navigating an often complex, and routinely challenging journey to support their neurodivergent children

"So, you've got all these professionals and opinions that you're trying to sort out and juggle what's right and who's sort of not lying, but who's not telling you the full truth for some reason", and

"We're gonna trying to get an EHCP [educational health and care plan] for Monarch at school. And so, I've been reading a bit about that and people's experiences and I'm already, you know, preparing for a bit of argument about what he should be entitled to" (Cypress).

Mothers' capacity to help their neurodivergent children frequently depended on their skills and abilities, knowledge of their children's conditions, and access to support, advice, and funding. For many of the sample, the challenges they faced seemed to be a daily factor

"Otherwise, I think it can be a bit like the Myth of the Sisyphus if you let it. Yeah. Like you're constantly pushing this rock up there and it keeps coming back. Sometimes it can feel a little bit like that" (Bellamy).

The mothers frequently acknowledged their need to advocate for their children

"I think that's the hardest thing about it, because as a parent you're expected to be an advocate and to be strong and to know what's needed, and say no, I I'm not happy with this and I'd really like it If you could try this, please, you know be quite firm" (Jupiter).

Accepting their own limitations, and personality constraints, several mothers resorted to external paid support for advocacy, and for many, this had helped them develop the skills, knowledge, and confidence they needed to take actions themselves

"We pay a woman, the woman who helped us with the EHCP. we've had loads of help from her. She's been really helpful with things that I just wouldn't have been able to do, things at school that I knew were not right, but I didn't know how to put it into writing. And I think she gives me confidence as well to speak to the school, and she's gone along to school meetings with me, initially every meeting that we had with school, she came too. But now I can go to school meetings." (Kingsley)

Jupiter discussed learning, and developing her capacity and confidence, to advocate for her children

"If something like that happened again, I would be going in there and I would be waiting at the door saying can I have a conversation and I'd be phoning the school. I've learned that if I don't do it, no one else will, you know, and I find all that really stressful." (Jupiter)

The mothers received practical support and advice from various sources. These included friends, family, other parents, charities, online resources, education and other local agencies

"... so it's emotional support, but also knowledge. Information sharing. So, there's a few mums ... I saw one yesterday who I've known a long time but would only see them once or twice a year in passing, but [as soon we] see each other, it's like, you know, straight in, in the weeds. What are you doing about this? What you're doing about that?." (Arden.

The diversity of information sources means that finding and accessing information could be challenging. The opening times of charities and institutional support agencies restricted their availability to many mothers. The mothers' capacity to effectively gather information, advocate, and support their children therefore varied and was acutely associated with their capacity to act themselves, or to access support either informally or formally. Ocean and Kingsley discussed advice and support

"One of the parents is also a SENCO [Special Needs Coordinator] at a school, and she talks to me and tries to help me. So, I just feel really fortunate having such a helpful, understanding bunch of people that we spend a lot of time with". (Kingsley)

Mothers both influence and are influenced by various factors that affect the outcomes of their caregiving efforts. These influences are significantly associated with their knowledge, skills, social networks, availability of time, support, involvement, and interaction with support agencies. Additional significant factors include the mother's life circumstances, health, family dynamics, and the conditions and behaviours of neurodivergent children.

In summary, identifying key capacities and capabilities of mothers caring for neurodivergent children can facilitate the development of support interventions. The four essential capacities and capabilities for effective caregiving are time, mindfulness, knowledge and compassion. These enable, and are enabled by skills such as time management, coping, emotional regulation, and social connections. These findings provide a foundation for developing initiatives to enhance mothers' resilience and coping skills.

Supporting mothers' well-being, enhancing their knowledge, and developing effective timemanagement strategies have emerged as crucial skills for managing diverse demands. The findings underscore the necessity of considering each caregiver's unique needs as an individual within their family, social context, and broader ecological environment.

Chapter summary

Figure 4-12 summarises the findings of this study. It identifies the two conceptual frameworks of conservation of resources, and assessment, and locomotion within regulatory mode. These frameworks provide a focus for identifying practical interventions for mothers caring for neurodivergent children to bolster resilience and enhance their coping capacities. Associations between the mothers' regulatory modes of assessment, locomotion, and resource caravans were determined. Links were identified between adequate resources and locomotion, and inadequate resources and a mixed assessment and locomotion orientation. These links are depicted in Figure 4-7 at the top and bottom within the blue oval, portraying the link between adequate resources and locomotion in blue and the link between inadequate resources and mixed orientation in orange.

The findings identified nine key resources for mothers caring for neurodivergent children. These are included on the left inside the blue oval and are numbered 1-9. The findings also determined how these resources could be clustered into five groups, recognised as resource caravans, and shown to the right of the nine key resources.

The analysis determined resource passageways for each mother, which were grouped to establish four resource passageways for the sample. These passageways are identified to the right of the resource caravans. The findings determined how the mothers' resource passageways were related to their regulatory mode. Data analysis identified relationships between resource caravan passageways and resource caravans, indicated by coloured connecting lines. The blue/orange shading on the inside right of the blue oval reinforces the association between locomotion and more empowered resource passageways towards the top, and a mixed assessment and locomotion orientation and more restricted resource passageways towards the bottom right.

Above the blue oval, social connections and time are depicted as key effects on the resource and regulatory mode situations. Beneath the oval, the visual depicts resources and regulatory modes that generally affect key capabilities and capacities, including compassion for oneself and others, wellness, knowledge, time management, and control.

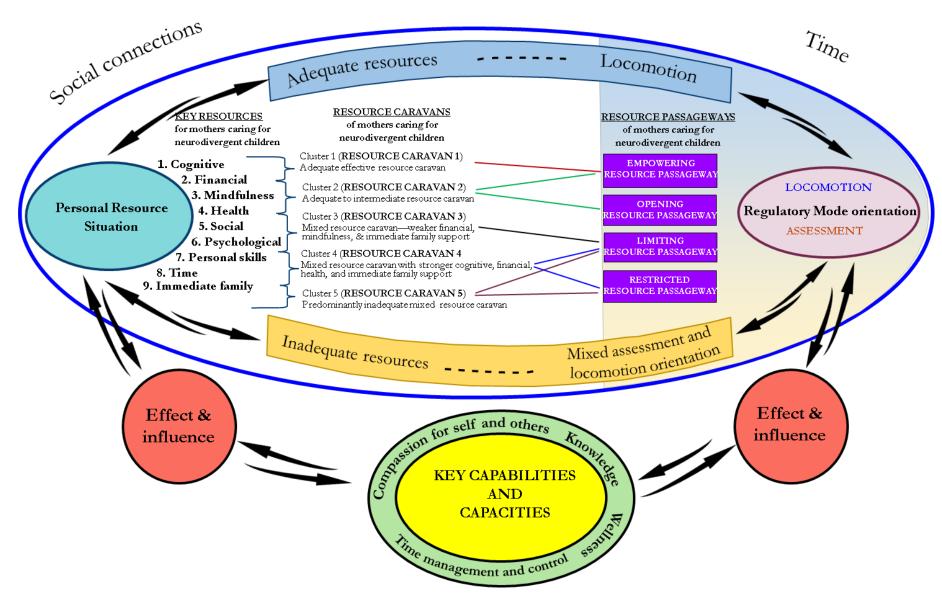


Figure 4-12: Diagram summarising the research findings (author devised)

5 Discussion

Introduction

This chapter conducts a critical appraisal of the findings presented in the preceding chapter and undertakes a comparative review of these findings with relevant previous literature. Where necessary, it questions prior literature and critically evaluates the data. This chapter is organised around the research questions (RQs). Each research question (RQ) will be addressed, and in doing so, I will identify my contribution to current knowledge, the theoretical implications, and potential future research directions. Two research gaps were identified in the literature review: associations between COR and regulatory mode, and how the two theories might be used to support mothers caring for neurodivergent children. Addressing each RQ, I will discuss the results of my analysis to determine how the two psychological frameworks of conservation of resources (COR) theory and assessment and locomotion within regulatory mode may work together. I also will address my overriding research question set out in RQ5, which is the identification of practical approaches to strengthen resilience and coping mechanisms for mothers caring for neurodivergent children. Developing support initiatives for mothers caring for neurodivergent children using COR and regulatory mode require understanding of whether the two constructs are associated, and work together. As this was not clear from prior literature, I believed that the initial objectives of this study needed to address that gap.

Data gathered to answer the research questions in this study suggest that key personal resources for mothers caring for neurodivergent children can be identified, and these resources can be clustered to form groups of distinct resource combinations, or resource caravans. Findings in this research found associations between mother's resource situations, and regulatory modes, and suggested links between resource passageways and their regulatory mode orientations. The importance of time and social support in COR and regulatory mode, and their relevance and importance to mothers caring for neurodivergent children, have also been highlighted. The findings contribute to the development of a practical approach to improve parental resilience and coping mechanisms, which could improve the well-being of mothers caring for neurodivergent children.

RQ1.

Assessment and locomotion orientation links to conservation of resources

This section examines how the two psychological frameworks used in this study relate to each other for mothers caring for their neurodivergent children. Understanding this was the initial step in identifying how they might be used jointly to support resilience in mothers and help enhance their coping capacity.

Regulatory mode provides two self-regulatory orientations: locomotion and assessment (Pierro et al., 2008). Locomotors focus on movement, progress, and goal achievement, while assessors concentrate on evaluation and review, and these orientations inevitably shape individuals' behaviours and decision-making processes (Lucidi et al., 2016).

According to COR theory, individuals strive to safeguard, obtain, and manage resources such as time, social support, and emotional resilience, which are important for maintaining well-being (Morris and Coley, 2004; O'Brien et al., 2014). Mothers in my sample actively sought support from diverse sources for themselves, and to enhance their children's development, which supports Kraus et al. (2019). Mothers looked to their families for emotional and practical support but also consulted Facebook groups for solace, advice, and information. Where they could, mothers found support from their children's schools and teachers, although this was not always possible.

The mothers in my sample faced a rollercoaster of calm peppered with periods of extreme demands on their resources. This led to stressors and psychological distress, as they navigated their caregiving responsibilities alongside work and family life commitments, which confirm similar findings by Morris and Coley (2004), and Sellmaier (2021). Mothers in my sample who had more healthy resource reservoirs were better able to focus on movement, progress, and goal achievement than those with weaker resource reservoirs. Those with more healthy resources acknowledged their difficulties, but maintained a more positive approach, seeking and finding positives within their inevitably challenging lives.

In line with Pierro et al. (2008); Sok et al. (2016), mothers in my sample who demonstrated locomotor orientations were more proactive, and organised, continually seeking solutions and progress. They mentioned using Google Calendar on their phones, and paper calendars. They understood the value of organising their lives, planning, and coordinating

their activities. They discussed routines and structure to help them organise themselves and their activities to prevent wasting time.

Although assessment and locomotion are considered discrete orientations, they function in concert, balancing the extremes of each other, with for example, locomotion reducing the limitations that can be caused by assessment traits (Lo Destro et al., 2017). My findings revealed a link between a locomotion orientation and well-resourced caravans. It would be reasonable to assume this connection, although the link cannot be identified in prior research. Established COR theory requires people to be able to productively invest their resources to protect against resource loss, recover from loss, and gain resources (COR Principle 2). Protecting or gaining resources can lead to emotional relief, and improved capacity to protect and gain resources (COR Corollary 3) (Hobfoll, 1989, 2001, 2012; Radford, 2024).

Effectively investing personal resources requires self-regulatory action, specifically, locomotion, to effectively initiate and progress goal directed activity. This concept supports recent findings of Loi et al. (2021) that people who are motivated to perform better, have higher locomotion traits. It also supports Beylat's (2024) reinforcement of Higgins et al. (2003) and Kruglanski et al. (2000), that locomotion accentuates an individual's focus on movement from state to state, to complete tasks quickly. The positive effects of locomotion on goal achievement are however acknowledged within the context that both assessment and locomotion contribute to self-regulatory successes (Kruglanski et al., 2000; Higgins et al., 2003). While regulatory mode research typically focuses on either assessment or locomotion (Mathmann and Chylinski, 2022), my findings suggested that a mix of assessment and locomotion is linked with inadequately resourced caravans. However, the connection was only identified in three mothers, partly due to the small sample size.

The circumstances faced by mothers caring for neurodiverse children, which require them to continually persevere with, and address challenges, may need some of them to rely on complementary regulatory mode orientations to keep pace with the demands they face when they lack extensive resource reservoirs. My findings linking mothers with inadequately resourced caravans and a mix of assessment and locomotion, may be rationalised by the concept of complementarity (Pierro et al., 2018) through which

individuals with limited resources depend on both assessor and locomotor orientations for a more positive effect, rather than relying on only one. Research on regulatory modes in social media sharing indicates that high construal levels (i.e. viewing situations more widely and abstractly) can facilitate the mixing and interdependence of regulatory mode orientations (Pham et al., 2023). Complementarity combines assessment and locomotion to allow the two orientations to work together, supporting and facilitating regulatory fit or balance (Avnet and Higgins, 2003; Kruglanski et al., 2000; Pham et al., 2023).

My findings contribute to regulatory mode and COR theory by identifying a connection between locomotion orientation and well-resourced caravans in mothers caring for neurodiverse children. They contribute further by identifying an association between a mix of assessment and locomotion, with poorly resourced resource caravans. My proposition that regulatory mode orientations may function together and complement each other through the concept of complementarity in mothers caring for neurodivergent children adds to regulatory mode theory (Kruglanski et al., 2000). It also complements previous literature examining how the two orientations can work together to address higher level goals (Chernikova et al., 2016; Mauro et al., 2009; Pierro et al., 2018).

Previous research has indicated that an assessment orientation is linked to insufficient and potentially constrained resource caravans, as assessor orientations are expected to prompt mothers caring for children to conserve resources through careful consideration, and focus on caregiving demands (Higgins et al., 2003; Panno et al., 2015). Assessor-oriented mothers should be more likely to evaluate options and strategies for themselves and their children, reflect on their effectiveness, and actively consider diverse approaches (Pierro et al., 2006; Panno et al., 2015). According to theory, they should typically allocate resources to optimise childcare while attempting to preserve their well-being and maintain their status quo, delaying action, and depleting their resources. These assessor traits were observed in only two mothers, but I found no clear link between an assessor orientation and resource caravan type; one mother had an inadequate resource caravan and the other had an intermediate caravan.

RQ2.

Key resources and combinations of caravans

Through RQ2, I wanted to determine the resources that were important and most pertinent to mothers caring for neurodivergent children. I also sought to identify whether the mothers in my sample could be grouped based on combinations of clusters of these key resources.

Key resources

The nine key resources I identified were cognitive, financial, social support, time, health, psychological, mindfulness, personal skills, and immediate family support. As no research was found that considered both COR theory and mothers caring for neurodivergent children, a comparison with the existing literature is not possible. However, literature on mothers caring for children with chronic illnesses is plentiful. These mothers are likely to experience similar challenges and stressors. Globally, research in this cohort has identified a range of resources needed by the mothers, including financial and personal skills (D'Arcy et al., 2021; Marfo, 2024), and time and its management (Heymann et al., 2010). Health resources (Heymann and Earle, 1999) and psychological well-being have also been reported as important (Hauge et al., 2015), and social and community resources from family members and others has been shown to support parents in navigating the care process (Babatunde and Akintola, 2023; Paintal and Aguayo, 2016; Shattnawi et al., 2021; Shaw et al., 2017). The burden of care often falls disproportionately on mothers and leads to increased stress and potential health problems (Brannan et al., 2018; Silva et al., 2009), emphasising the importance of close family support (Payne et al., 2012). Mindfulness and its links with COR theory have been studied in an employment context, and it has been proposed that COR theory may explain why mindfulness contributes to work motivation and performance (Hyland et al., 2015; Kroon et al., 2015), and this may also be relevant to motivations and performance in mothers caring for neurodivergent children, which can take-up so much of their time. The presence of these resources is likely to be important for mothers caring for neurodivergent children, as families with more resources are generally better able to shield themselves from further resource losses (Brannan et al., 2018).

Prior research on parents caring for long-term sick children appears to support the nine key resources I developed as salient for mothers caring for neurodivergent children. However, as the literature does not consider COR and mothers caring for neurodivergent children, my findings contribute to COR theory by adding knowledge on prominent resources for this specific group, and further, contributes by identifying key personal resources in mothers caring for neurodivergent children. As previous COR research considered the theory's application to parents caring for chronically sick children, it is also likely that the results of this study may be generalisable to that group of parent caregivers. It may potentially be more widely applicable to parents providing acute, longer-term childcare, and possibly children caring for aged parents with significant ill-health.

Having established nine key personal resources for the mothers in my sample, I next sought to determine whether the mothers could be grouped based on combinations of these nine key resources.

Resource caravans

People's resources are individual-specific, do not function in isolation, but work with, and are dependent on other resources, creating resource groups or caravans (Hobfoll, 2011). Higher levels of individual resources, even only one resource, have been shown to increase an individual's overall resource levels (Hobfoll, 2001) through the positive effects of resources on other resources.

I identified five qualitatively distinct combinations of the mothers' key resources that differed in makeup and quality of resources. The resource groups portrayed resource caravans of the key resources for each mother. They comprised four resource caravans and an individual cluster of key resources which did not align with any of the identified groups. Caravan 1 was a resource cluster where each key resource was adequate. Caravan 2 was a cluster in which the nine resources were either of an adequate or intermediate level. In the two weaker resource caravans, caravans 4 and 5, caravan 4 clustered adequate, intermediate, and inadequate level resources, with adequate cognitive, health, and immediate family support, and predominantly adequate financial resources. Resources of mindfulness, psychological and personal skills, time, and social support were all inadequate. Caravan 5 clustered predominantly inadequate and intermediate level resources. Caravan

3 categorised a mixed cluster of resources for one mother whose resource cluster did not conform to the other four caravans.

The two stronger caravans, caravans 1 and 2, clustered adequate or intermediate levels of each resource. The strongest resources were cognitive, health, social, personal skills, and immediate family support. Although all resources in caravan 1 were adequate, there were varied profiles in caravan 2 for financial, mindfulness, psychology, and time, where the resource levels were either adequate or intermediate. Two mothers had intermediate resource levels for social and personal skills, but otherwise, these two key skills were adequate for all mothers in the group. Immediate family support was adequate for most mothers. Overall, caravan 2 was weaker in finance, psychological, and time, suggesting that the mothers would benefit from support in these three resource areas.

Caravan 4, the first of the two weaker caravans (of caravans 4 and 5) was a mixed-resource caravan in which all mothers had stronger cognitive, financial, health, and immediate family support resources. Conversely, they generally had weaker mindfulness, social, psychological, personal skills, and time resources. Caravan 5 was the last and weakest grouping of resources. It demonstrated a predominantly inadequate mixed-resource caravan, in which only cognitive, and health, were either adequate or intermediate, with all other resources being inadequate or intermediate. My findings suggest that mothers in the two weaker caravans would generally benefit from help with psychological, time, mindfulness, finance, personal skills, social, and immediate family support resources.

Mothers with better resourced caravans spoke more positively about their lives and coping abilities. They generally demonstrated a better understanding of how best to support their neurodivergent children. Some of the mothers attributed this to their knowledge of the children's conditions, and to their ability to communicate what they knew, both verbally and in writing. Each of them had effective community and social links, supportive husbands or established partners, and their life courses had been more advantageous. They talked about sharing responsibilities with husbands who were jointly involved in their children's care. Mothers discussed their close networks with peer-mothers who cared for neurodivergent children, with whom they socialised and felt comfortable. The mothers found these peers non-judgemental, helpful and supportive, through a shared understanding of each other's problems and experiences.

Conversely, mothers with resources that formed weaker caravans were generally less positive and had limited or no community or social links. These mothers talked about having no social life and linked this to never feeling able to leave their children and having no-one to leave their children with. They perceived a lack of family or community understanding of their neurodivergent children's behaviours, and their own parental responses. Those with friends and family spoke of feeling they were judged negatively by them and felt this affected their social and family relationships.

These parents also generally talked about having a poor, or less positive life-course which continued to impact their current lives. They spoke of broken, dysfunctional families, and their parents divorcing. They recalled moving in with grandparents and controlled, stifled upbringings. They mentioned being bullied at school and less than satisfactory educational experiences.

Considering all caravans, the least positive resources for mothers were psychological, time, mindfulness, finance, social, personal skills, and immediate family support. The absence of the first four of these resources were evident in each caravan except for resource caravan 1 where all resources were adequate. The key personal resources will be discussed again under RQ5 which considers interventions to support mothers caring for neurodiverse children where they become the focus of the proposed areas of support.

My analysis revealed key resources and resource caravans for mothers who care for neurodivergent children. It is possible that the findings may be relevant to individuals in similar caring situations, but further research is required to validate this. My findings significantly contribute to COR research by identifying that there are prominent resources for mothers caring for what appears to be a previously unresearched group. The findings also recognise resource caravans for a cohort of caregivers which may have practical value for developing important interventions for support in a growing global population. Although my research sample were geographically confined, it is likely that all parents caring for neurodivergent children will experience similar challenges and restrictions. By establishing these new theoretical assertions, my findings expand COR research into an area that has not been previously addressed.

RQ3.

Resource passageways, resource caravans, and links to regulatory mode

Resources develop and operate mutually, forming individual-specific caravans of resources where strength in one or a few resources can positively influence other resources (Hobfoll, 2012). Similarly, self-regulation orientations affect how individuals manage, adjust and change aspects of their lives through their assessment, and locomotion proclivities, meaning that their self-regulatory responses are not universal. Responses are shaped by a range of factors which are influenced by both their past and current circumstances (Pierro et al., 2008; Pierro et al., 2011).

An individual's resource situation is determined by factors which include their ecology, social environment, family, work, and the effects and impacts of their life course (Hobfoll, 2011). Conservation of resources (COR) theory assumes that people use key resources for self-regulation, maintenance of social relations, behaviours, and cultural fit, and this assumes a common need for well-being, self-preservation, family, and positive sense of self (Hobfoll, 2012). Adversities affect these factors in an individual's ecology and can result in cycles of loss which can be wide-ranging, rapid, and sustained (Hobfoll, 1991). This was observed amongst the mothers in my study.

Resource caravan passageways

Resources were intrinsic to several domains of the lives of mothers in this study, and the distribution of those resources was unequal, which is in line with research by Hobfoll, (2011). This make-up of resources was linked to a variety of factors associated with the mothers present and past, which shaped and influenced how they used, maintained, and developed their resources. Resources evolve and prevail collectively as resource caravans, which are supported or repressed by conditions that are referred to in COR theory as resource caravan passageways (Hobfoll, 2012). Individuals may benefit from their resource passageways as they can influence and support the development and maintenance of resources, or conversely, they may suffer situationally or chronically through risks to, or depletion of existing resources (Dannefer, 2003; Elder, 1998; Johansson et al., 2007; O'Rand, 2009; Ye, 2024).

In COR theory, advantageous resource passageways typically evolve from affluent, prosperous, secure neighbourhoods, with good healthcare, and schools, and favourable social connections (Hobfoll, 2011; Kaur et al., 2024). Poor resource passageways commonly result from impoverished communities, with less effective education, healthcare, support, and less-advantageous social connections (Hobfoll, 2011). Consequently, studies in COR argue that that individuals with poorer passageways which lack evolved resources, have limited resource reserves to cope with stress and are more vulnerable to negative emotions, thoughts, and experiences, whereas individuals with advantageous passageways have greater reserves of resources, and are less vulnerable (Hobfoll, 2012).

Consistent with the findings of Hobfoll (2011, 2012), this study identified life-course components that influence mothers' current resource situations through their resource passageways. A comprehensive analysis is presented in Appendix X. The descriptions employed to delineate distinct resource passageways highlight a spectrum of passageways beyond merely enabling and constraining. The analysis of mothers' comments in this study suggested that various resource passageways shaped by childhood and adult experiences impacted their current resource situations. Each mother was categorised into one of the four distinct resource passageways. I have termed these empowering, opening, limiting, and restricting resource passageways.

The unique characteristics of these four passageways facilitate the alignment of each mother with one of the five resource caravans identified in RQ1. Empowering resource passageways were associated with the previously identified better-resourced caravans 1 and 2, although some mothers in Caravan 2 exhibited an opening resource passageway. This indicates a positive progression from a limited opportunity to early life. Consequently, mothers in the better-resourced caravans 1 and 2 possessed a resource passageway that was either consistently positive or became more positive over time through an opening passageway. Conversely, limiting and restricting resource passageways were predominantly associated with less well-resourced caravans 3, 4, and 5.

My findings complement COR research on resource passageways by recognising and reinforcing the concept that passageways can develop and evolve through the impact of people, agencies, and the opportunities, or the constraints that individuals experience

during their life course. My findings also confirm that the concept of resource passageways applies to mothers caring for neurodivergent children, which has not been acknowledged previously. Resource passageways are aligned with cumulative advantage and disadvantage theory (Bask and Bask, 2015; Ferraro and Morton, 2018). Cumulative advantage is the phenomenon in which personal resources accumulate through access to opportunities and resources over time (Dannefer, 2003; Elder, 1998; O'Rand, 1996). Cumulative disadvantage occurs when there is loss of, or failure to accumulate resources through prolonged experiences of disadvantage, or limited access to opportunities and resources at critical points (Johansson et al., 2007).

Challenging the starker assumptions of cumulative advantage and disadvantage, my findings show that while a more advantaged and supportive childhood can, and is likely, to lead to a more positive later life, it is also evident that a restricted early life and a challenged later life are inextricably linked. Although I noted examples of limited, challenged early lives creating similarly limited and challenged current lives, analysis of the data suggested that individuals can influence, affect, and change their lives for the better, and this change appeared to be substantive rather than situational. The mothers in my study experienced similar challenges through their caring responsibilities, but the diverse evolution of resources during their lives, associated with their individual passageways led to significant differences in their well-being, and capacities, in their current lives. Listening to and understanding the stories, concerns, descriptions, and lived experiences of the mothers in this study revealed the complexities and nuanced evolution of their resource passageways. My data complements but also develops the cumulative advantage and disadvantage theory by nuancing its concepts and principles.

Resource passageways and regulatory mode orientations

I compared the four resource passageways I had developed for the mothers with the associations between resource levels and regulatory mode orientations I identified in RQ1. I had determined an association between adequate resource levels and locomotion mode, and between limited resource and mixed assessment and locomotion. Incorporating these associations with my findings on resource passageways, I also established an association

between more positive resource passageways and locomotion, and more challenged resource passageways, and mixed assessment and locomotion orientations.

By determining the four resource passageways for mothers caring for neurodivergent children, I have identified the potential for multiple passageways not previously identified either for mothers of neurodivergent children, or generally, within COR theory. These proposed four passageways contribute to existing research on resource passageways and may more widely, be applicable generically to the passageway construct. My research confirms that resource passageways influence an individual's current resource level, which underscores existing research. However, my findings also suggest that resource passageways may influence and be influenced by a regulatory mode orientation, implying a link between the two constructs. As there appears to be no previous research looking at regulatory modes and resource passageways, my findings contribute to the body of research in both regulatory mode and COR theory through these possible associations.

RQ4.

What are the roles of time, and social support?

Introduction

Prior literature in conservation of resources (COR) theory, and regulatory mode, considers time, and social support. People seek social support as a resource (Hobfoll, 1989), and stronger, effective attachments enhance other personal resources, helping people combat stressors and negative resource spirals (Meng and Choy, 2021), which reduces negative outcomes, including burnout (Karatepe, 2015). For mothers caring for neurodivergent children, social networks and support sustained and developed influential resources (Blackmore et al., 2007), helping them address the routine demands and challenges they encountered. Through the lens of self-motivation, Carvallo et al. (2016) examined instrumental and emotional support and noted that the former helped individuals struggling to control action ineffectiveness, and the latter supported self-value ineffectiveness.

Research in COR theory has considered time to be an essential resource used by people to protect and obtain personal resources (Bell et al., 2020), and in regulatory mode its temporal capacity is acknowledged for its ability to support movement from a current to a

desired future state (Kruglanski et al., 2016). For the mothers in my sample, poor time use could be frustrating and lead to negative psychological effects, but its effective use provided better goal achievement, positive affect, well-being, and could facilitate greater social connections, with resultant support and happiness. Time was significant for the mother's work and life balance, because limited time restricted activity, suggesting time was a key factor for satisfaction, coping, and self-efficacy.

Pfeffer and Carney (2018) found that ineffective time use could lead to impatience, diminished meaning from work effort, and psychological distress. This was also evident from my findings, where mothers could be impatient, perceiving that their efforts were pointless, and ultimately stressful for them. This was frequently associated with comments about support institutions, and was often linked to their children's education, and grants for funding. Mothers found the application processes draining, time wasting, and requiring excessive and unnecessary paperwork.

Literature identifies that time helps people socialise, which can lead to increased happiness (Mogilner, 2010). Mothers in my sample reinforced this whilst revealing the challenges they had finding the time to commit to socialising. They talked about positive benefits from seeing friends, but routinely mentioned how difficult it was to fit this in alongside their diverse other responsibilities. This was particularly so for mothers with more significant work roles.

Research has documented the complex relationships between childcare and the resources of time, work and income (Kaaria et al., 2024; Thorpe al., 2024). Fan et al. (2021) found that effective collective functioning of time and personal finance improved financial, family, and childcare satisfaction in mothers caring for children with long-standing illness. They found that working longer hours, evening work, and taking on managerial roles acted as lasting time-based resource demands, which inhibited personal childcare time and satisfaction. Studies by Agostinelli and Sorrent (2021) and Bastian and Lochner (2020) considering the money-time trade-off, found that increased maternal work hours impacted negatively on the quality of mother-child interactions, particularly for parents with younger children and in lower-income families. Brown et al. (2008) found that over time, working part-time or from home with a network of local support, facilitated resource accumulation, and improved work-life balance. Remote work can offer benefits to parents of

neurodivergent children by enhancing flexibility and reducing commuting, stress, and work–family conflict (Braniki et al., 2024); Kalmanovich-Cohen and Stanton, 2023; Miktas, 2024).

Regulatory mode literature has compared the effects of valuing time more than money or like money and records negative social effects from valuing time like money, including reduced prosocial engagement and the adoption of more self-focused activities (De-Voe and Pfeffer, 2010; Whillans and Dunn, 2015). Valuing time more than money can result in subjective well-being and contentment (Lee-Yoon and Whillans, 2019), and individuals who value time more than money have been found to make decisions that enhance their available time (Hershfield et al., 2016; Whillans and Dunn, 2019). More time may help individuals socialise and find greater happiness (Mogilner, 2010). My findings showed that all but one of the mothers valued time more than money, which suggests that extreme time challenges may place certain cohorts, specifically mothers caring for neurodivergent children, outside the scope of such findings.

For mothers in my study, time and child-focused interaction time were significantly important resources, and finance was generally less significant. This may be partly because where salaries were reduced, mothers augmented family incomes by applying for grants and allowances to allow them to meet their financial commitments. My findings suggest the mothers strived to balance their work, time, and childcare commitments to achieve satisfaction, resource security and accumulation. Several accomplished this by taking on shorter hours and working from home, which allowed them to continue working whilst benefiting from greater child-time. My findings support and therefore contribute to recent research in this area (e.g., Agostinelli and Sorrent, 2021; Braniki et al., 2024); Brown, 2008; Kalmanovich-Cohen and Stanton, 2023; Miktas, 2024).

Although income was not a dominant resource, it was nevertheless valued by the mothers. Income was associated with perceived self-efficacy, provided security, flexibility, independence, and improved capacity to provide for their neurodivergent children. In this way, income supported both emotional and financial security. It helped the mothers advocate, meet the specialist needs of their children, buy the food they demanded, and pay for specialist schools and attend much needed activities. One mother with a full-time managerial role spoke of the challenges of balancing work and childcare. She felt she had

too much work and not enough hours in the day, which resulted in her spending less time with her children and husband than she wanted. Another mother created flexibility to balance all her demands, doing her work before her children got up and after they had gone to sleep at night to allow her to meet her work demands and commit time to her children's needs. Fan et al. (2021) found that mothers with higher pay and more demanding managerial roles could compensate for the consequential reduced personal childcare time because it allowed them to spend more on their children (Rockwool Foundation Research Unit, 2010). My findings support this, and although all the mothers focussed their attention on their neurodivergent children, greater incomes did lead to greater spending on children. However, it was not clear that this was in compensation for less childcare time, as it may be that higher incomes simply facilitated greater spending.

Whilst higher salaries provided significant benefits, they also tended to restrict the mothers' options. Mothers with higher incomes were those who said they would find it more challenging to reduce their income. They felt they were unable to lose the benefits they now had and that lower incomes would negatively affect their children.

One sub-theme identified in my study highlights that mothers caring for neurodivergent children find that the use of their time needs to be controlled, simply because it is limited. This is linked to other subthemes identifying why and how mothers controlled their time, which will be discussed later in this section.

That time is limited for mothers caring for neurodivergent children is not surprising; however, the underlying factors and consequences are salient. A study by Trougakos et al. (2014) considered the value of lunchbreaks at work, the outcomes of which may be applicable to this study. Trougakos et al. acknowledged the value of lunchbreaks but found employees experienced lower fatigue if they had autonomous control over their activities during the period. This is underscored by the mothers in my sample who benefited from mastery over their activities, and so they persistently strived to control the time they had, because better control led to improved management of stressors, with consequent well-being and satisfaction. Some mothers mentioned experiencing stress if they were not able to control important aspects of their lives, specifically factors associated with their children. They strived to have control, learning how best to approach routine issues, and

endeavoured to gain, or regain, control when they perceived they had lost it to, for example, local authority or educational institutions.

The overarching need to control time was evident in my sample and the time sub-themes I established support this. Key amongst these were that neurodivergent childcare is more time-consuming than the care of other children, limited time limits activity, and there is a need for mothers caring for neurodivergent children to allow themselves time for personal well-being. The link between time and well-being reinforces prior research including that of Lock and Dunn (2022) and Okada and Hoch (2004), which found that the way people value time can have cognitive consequences and influence their emotions, attitudes, and behaviours. My finding that mothers need time for personal well-being complements this.

Lack of time can lead to perceived physical and psychological depletion (Akram and Akram, 2019) and to feeling drained and overstretched through resource depletion (Maslach and Leiter, 2008). The loss of resources such as time, results in decreased coping options and psychological distress (Cohn et al., 2020; Asbury et al., 2021). Mothers in my sample talked about feeling that their lives were closing-in-on-them when they became overburdened, which affected them emotionally. They became frustrated with their lack of time and inability to affect their situation. More positively, time helped mothers socialise and gain from social connections to address resource challenges and loss. This supports findings by (Mogilner, 2010).

My time subthemes captured how mothers dealt with their time limitations to create adequate personal childcare time, and the importance they attributed to this endorses prior research (Hallberg, and Klevmarken, 2003; Milkie et al., 2010). Mothers who were most successful in time use and management had a locomotion orientation and adopted time-management techniques noted in regulatory mode research as being predominantly used by locomotors. Key techniques for ensuring successful time management were multitasking, prioritising, flexible time use, routines, and focusing on tasks that could be accomplished in the short-term. This finding contributes to regulatory mode research.

Multitasking is a typical behavioural consequence of locomotion that supports time management (e.g. Pierro et al., 2013) as it reduces the time committed to individual goal pursuit. However, it can also result in less care (Payne et al., 1996), and potentially reduced

accuracy (Mauro et al., 2009). Mothers often spoke positively about their ability to prioritise, whether notionally, or practically, and showed pride in their capacity for multitasking. They spoke about the benefits of being flexible and extolled the virtues of the routines and efficiencies they had in their everyday lives. The mothers in my sample confirmed the five derivations of time related to locomotion that were proposed by Kruglanski et al. (2016). They mentioned their focus on achieving tasks quickly and easily, prioritising more achievable tasks, multitasking, and initiating decisive gaol related actions. Through these techniques, the mothers could manage their time relatively effectively, with limited wasted time, which resulted in reduced stress and greater satisfaction.

My findings also support regulatory mode findings by Loewenstein et al. (2003), that locomotors were likely to exchange longer-term rewards for less valuable short-term incentives, a form of temporal discounting (Lowenstein et al., 2003; Villmoare et al., 2023). My findings do not appear to support a finding by Lin et al. (2019) in a prior COR study that people may prefer to adopt a longer-term approach to resource investments to gain greater future returns. A subtheme for mothers in my sample was that the short-term approach was their norm. This difference could be attributed to the specific challenges faced by mothers caring for neurodivergent children or, more generally, mothers facing continual time challenges and difficult choices over priorities.

Social support

Social connections for the mothers in my sample came from a variety of domains but routinely through family, friends, other parents, and the work environment. Although social connections varied and were not always positive, the associations could provide psychological comfort, encouragement, reassurance, friendships, and practical advice, which helped the mothers take-on their daily challenges. These findings are in-line with, and contribute to COR research, identifying a direct link between social connections and positive engagement (Hobfoll et al., 2012).

The importance of work based social connections is also validated in COR research, which frequently highlights the importance of work and colleague attachments (e.g. McTiernan et al., 2016). These work-based attachments can act as a resource for mediating resource loss, supporting resource gain, and preventing negative outcomes, including burnout

(Karatepe, 2015). Mothers spoke of the social networks they had developed in and through the workplace. They mentioned the satisfaction they had from the work they did, being appreciated and valued, and the perception that what they did was important. These amounted to significant resource gains which offset their accumulated resource losses.

Mothers valued the sense of belonging and acceptance that their social connections brought, echoing Baumeister and Leary (2017), because as Leary (2005) found, failure to belong can result in misunderstandings, social exclusion, and a loss of support from others. The importance of acceptance, belonging, and consequent support was confirmed by the mothers. Some considered their friends amounted to an extended family that they had chosen for themselves. These small close networks were often augmented by less-close acquaintances. Overall, the mothers derived help and support from these networks and the reciprocal relationships they created.

The reassurances they derived from these friendships had a positive and significant impact on the mothers, who commonly found support for their negative psychosocial experiences, worries, and anxieties. This supports the findings of Kane et al. (2012), Marigold et al. (2014), and Qi and To (2025) that people turn to close others for support with stressors and to deal with negative moods. Social networks are important for both mothers and their neurodivergent children (Mullins, 2024). Mothers' comments related how they valued their social networks with peer-mothers who had neurodivergent children. These small close networks allowed them to communicate with and exchange experiences and concerns with mothers who could understand the lives they led and the problems they faced.

Social context is highlighted in both COR theory and self-regulation (e.g. Hobfoll, 2011; Zee and Kumashiro, 2019). Positive characteristics associated with constructive social support are particularly associated with locomotors who are likely to welcome support from close others, with consequently increased engagement and goal pursuit (Zee and Kumashiro, 2019). Engagement has been shown to significantly influence psychological and physical functioning (Uchino et al., 1996). This supports my subtheme of psychological comfort and encouragement associated with the mothers' social connections. All the mothers identified as locomotors made extensive, effective, use of social support. They gained a sense of common purpose from these networks, but also the knowledge, information, ideas and advice they provided. The mothers benefited most from

sympathetic peers who were interested and willing to listen. These networks calmed them, bolstered their self-image, and provided positive support. Contact was frequently not face-to-face, but was often via text, chats, or e-mail.

This subtheme recognises the crossover model (Chen et al., 2015) and broaden and build mechanism (Frederickson, 1998, 2000), both of which are routinely considered in COR research, although they do not appear to have been previously studied in the context of mothers caring for neurodivergent children. My findings therefore contribute to previous research studies. Crossover identifies the passage of positive and negative resources such as emotions and experiences within work and social frameworks and broaden and build argues that positive emotions signal the development of resources and greater wellbeing. For mothers in my study, broaden and build, and crossover were relevant in their social and work environments. In the latter, mothers drew from work colleagues, clients and customers.

Another positive subtheme of social support was practical help and advice, which, although often difficult to access for some mothers, was valued when it was, as it could provide practical guidance, tangible resources, and resolve difficult blockers to achieve important goals. This is a finding which complements research by Cohen and MacKay (1984), and Feeney and Collins (2014).

The need for support was common amongst the mothers, although they were frequently challenged accessing it. Sources of support for their children and family were not easily found and mothers used much of their time trying to find it. Easier access to support or guidance on where to find it, was something the mothers would value and find particularly helpful. One mother described paying for help to prepare an education health and care plan for her child, and subsequent support submissions. This helper had also supported her to address issues with her child's school that she had not felt confident to deal with herself. Through this support, the mother had developed the ability and self-confidence to tackle problems and address many subsequent issues herself.

Despite the positive subthemes developed, social connection also brought challenges maintaining relationships with people who found it difficult to understand the neurodivergent children's condition and behaviours, and because friends and acquaintances could not relate to the experiences and challenges of the mothers. The negative aspects of social support were also linked to two other subthemes identifying that family and sibling support could be variable, supportive, or unsupportive, both psychologically and practically.

RQ5.

What practical interventions and approaches can be identified for mothers caring for children with neurodivergent conditions to support their resilience and enhance their coping capacities?

Resilience and compassion

To discuss this RQ, I will first clarify resilience and coping, then the challenges and needs of mothers caring for neurodivergent children. I will conclude with my proposals for developing support solutions, drawing from the conclusions of my RQs. I complete the chapter with a conclusion of my findings.

Parents caring for children with neurodivergent conditions routinely experience difficulties and hardships (D'Arcy et al., 2021). The challenges they face are unique (Reddy et al., 2019) and more significant than those of other parents (Cousineau et al., 2019) with higher levels of parental anxiety than controls (Amorim et al., 2020). In these circumstances, maintaining and increasing resilience is vital if parents are to successfully deal with the adversities they encounter (Cousineau et al., 2019).

Resilience is the capacity to not just bounce-back, but also to endure and recover from difficult experiences, to become more able, and robust (Rolland and Walsh, 2006). This is a positive process in the face of considerable and often consistent difficulties. It requires learning from personal struggles to become stronger, more positive, adaptable, knowledgeable, and able for the future despite distress and anguish (Khu et al., 2019). An individual's resilience and broader well-being can be affected by various factors, some of which can be modified. These factors may be genetic, associated with active stressors or learned assessments, and affected by coping skills or access to support (Schneiderman et al., 2005).

In COR theory, resilience refers to people remaining vigorous, committed, and engaged in important life tasks, even under stressful circumstances (Chen et al., 2015). Using COR principles, Bardol and Drago (2021) proposed two types of resilience: acceptance, and strategic. Both use positive actions to respond to adversity, but the former is resource-preserving, and the latter is resource-enhancing. In COR theory studies, resilience is not considered to be a fixed characteristic, but a facet influenced by supportive social interactions and enabling environmental structures which can be increased through resources such as hardiness, self-efficacy, self-esteem, and social support (Chen et al., 2015). Social resources are associated with better emotional outcomes under stressful circumstances (Hobfoll et al., 2003; Ren et al., 2025), with the support and resource gain being important for preventing stressors, and for post-stress mediation (Westman et al., 2004).

Coping embraces the active assessment of challenges and requires significant expenditure of resources to address them. People cope better if they can modify their thoughts, emotions, and behaviours (Lazarus, 1993), and this can be achieved through self-regulation, using emotion-focused and problem-solving techniques and approaches. Emotion-focused modification seeks to adjust the way we approach a stressor or diminish its emotional impact. Problem-solving coping occurs when we adapt to our condition by changing or adjusting the stressor or our perception of it (Lazarus, 1993). Sarriá and Pozo (2017) found that parents of children with autism may use strategies including emotion-focused coping or avoidance and distraction, noting greater use of positive and problem-solving strategies by mothers than fathers. For mothers caring for neurodivergent children, the beneficial effect of an adaptive coping approach is the development of productive stressor responses, leading to improved quality of life for the family (Hudson, 2016).

Coping can be supported by self-compassion, routines, and social support, which can reduce stress and depression, and improve well-being (Kemp, 2024; Neff and Faso, 2015; Schlebusch, 2015). Developing meaning through optimistic reviews of experiences has been shown to enhance parents' situational appreciation and tolerance and increase their perception, confidence, and empathy, ultimately helping them adapt to, or accept, their situation (Altiere and Kluge, 2009; Predescu and Sipos, 2013; Sarriá and Pozo 2017).

Significantly challenged parents, particularly mothers, have been found to undergo positive gains, despite their ongoing stressors, not just to cope, but to find positive meaning. (Matenge, 2013; Fewster, 2014).

The mothers in my sample used practical coping approaches, including control, routines, time management techniques, multitasking, and accommodating the needs and demands of their neurodivergent children. One mother ironed her sons clothes each morning before handing them to him to put on because she believed it made him feel more comfortable to wear fresh, warm clothes. In other cases, past experiences helped the mothers deal with their children, for example by allowing neurodivergent children to be disruptive when they went out for a meal, knowing that they would eventually settle. Other mothers used distraction techniques, such as keeping each of their children occupied safely in separate rooms at home or just allowing their children to spend time watching the television.

Mothers developed the ability to deal with their children's demands and behaviours to avoid conflict, which could be personally challenging and require cognitive-coping strategies. One mother spoke about her daughter's extreme controlling behaviour towards her, describing herself as her daughter's remote control, something she was content to accept. Mothers frequently used activities, including work, as a respite in home situations to help them cope, and maintaining self-satisfaction and positivity despite their challenging childcare burdens.

Social connections, self-empowerment, knowledge acquisition and sharing, and a sense of community and belonging were frequently referred to, with many mothers using their skills to help peer-parents. Being able to help other mothers was frequently mentioned as a positive, rewarding experience. One mother had completed mindfulness training and planned to develop a local retreat and teach mindfulness to other mothers. Mothers in my sample who managed to reframe their lives through effective coping appeared to be more capable, stronger, and positive, and more likely to perceive hope for themselves and their families.

For the remainder of this chapter, I will use the phrase 'mothers caring for neurodivergent children' and parents caring for neurodivergent children interchangeably. This is partly to

account for cited references, but also because the point being cited is likely to apply to mothers or fathers.

Challenges and needs

Aspects of the demographics of the mothers in this study are now considered, along with findings from the research question (RQs) to support the development of practical approaches to strengthen resilience and coping mechanisms.

Findings from RQs1-4 identified various factors that could help support resilience and enhance the coping capacities in mothers caring for neurodivergent children. RQ1 assessed mothers' resource caravans at the time of their interviews based on the adequacy of their resource situations. Five resource caravans were established in RQ2, with the strongest resource caravan, caravan 1, comprising mothers with adequate resources. The weakest resource caravan was caravan 5, comprising mothers with predominantly inadequate resources. Demographic data revealed that mothers with adequate resource caravans were younger than the sample mean, and their average age at childbirth was less than the whole sample. Each mother was married or had a steady partner who was supportive, and all except one had good community links and effective social support networks. In RQ3, the life-course of each of the mothers, reflected through their resource passageways, were all positive. Conversely, mothers with inadequate resources in caravans 4 and 5, were older than the sample mean and their average age at childbirth was greater than the mean. Some mothers were married with supportive husbands, but more were single and without support. All except one of the mothers had no or few community links and all had limited social support. The life-course of each of these mothers, as reflected through her resource passageway, was poor.

For this RQ, the salient positive factors were the mother's age, their age at the birth of their children, availability of emotional and practical help within their immediate family, effective social and community support, and positive resource passageways.

Prior research associates social support with better outcomes in stressful situations (Vaux 1988), and the important role of family and social support is widely acknowledged in neurodivergent-care literature because of its positive effect on life satisfaction and wellbeing (Halstead et al, 2018; Lovell and Wetherell, 2019). The negative effects of poor

support have been shown to lead parents caring for neurodivergent children to limit social activities because of stigma and discrimination (Lovell and Wetherell, 2019; Reddy et al. 2019; Zuurmond, 2019). These negative outcomes indicate the need for support initiatives that incorporate mechanisms to help mothers deal with negative attitudes, develop effective assistance from close and wider families, and maintain and develop opportunities for community and social support. My analysis of the data also suggests that the success of support packages could be affected by the mother's age which more broadly, may reinforce the need for bespoke approaches when developing support initiatives. The need for individualised approaches has also been identified as an important factor in recent studies (D'Arcy et al., 2021; Shepherd et al., 2018; Tollan et al. 2023; Vaz et al., 2022).

Income was not a major concern for my sample, although finance was frequently discussed, and was impactful. Mothers in the weaker caravans 4 and 5 made more negative comments about their income and financial situation than mothers in the stronger resource caravans. This suggests that help with financial issues may be particularly relevant for mothers with more challenging resource situations. This finding reinforces prior research suggesting that finance is raised more forcefully if it is a concern (Brown et al., 2008; Scherer et al., 2019). Notwithstanding the level of concern attributed to finance by some of my sample, access to financial advice would be advantageous in any support initiative.

RQ1 determined that mothers with a dominant locomotion orientation also had adequate resource caravans. This suggests that the factors that distinguish locomotors may support resource retention and generation. The beneficial factors distinguishing locomotors are identified in the regulatory mode postulates and derivations (Kruglanski, 2016) which are considered in the linked section Regulatory Mode Postulates and Derivations (page 36), and include time management, primacy of goal achievement, promptness in task initiation and action, and speed. Awareness of, and training in these locomotor techniques as part of support interventions may help to encourage and develop locomotion approaches that can refine and improve approaches to time management. The finding in RQ1 that inadequate resource caravans are associated with mixed assessment and locomotion orientations may support this concept, as people with mixed orientations may lack understanding of, or use of the techniques needed to adopt a more locomotor approach to gaol achievement.

RQ2 identified key resources for mothers caring for neurodivergent children and how clusters of these resources could be grouped to form five resource caravans. Nine key resources were prominent because of their influence on the mothers' lives. These resources relate to financial situation, social support, time, health, cognitive, psychological, mindfulness, personal skills, and immediate family support. The most limited resources amongst all the mothers were mindfulness, psychological skills, time, personal skills, and social skills, but inadequate levels of all resources were noted in mothers with weaker resource caravans 3 and 5. Mothers with more effective resource caravans 1 and 2 showed weaker time and psychological, financial, and mindfulness resources. This suggests that interventions should particularly seek to bolster the following resources.

- Mindfulness
- Psychological
- Time
- Personal skills
- Social connection
- Finance

RQ3 established that more positive and negative resource passageways were associated with corresponding positive and negative current lives, although current lives were not inextricably linked to the individual's life course. Challenged passageways could be improved by effective and meaningful interventions, as demonstrated by the proposed opening resource passageway identified in my findings. Establishing the potential to improve the lives of the mothers in my sample supports previous literature showing that support programs and interventions can improve the lives of parents caring for neurodivergent children, and develop resilience and coping skills (Cousineau et al., 2019; Guralnick, 2023; McConkey et al., 2023).

The importance of time and social support for negating damaging emotional and psychological effects is established in RQ4. This underscores prior research identifying that parenting children with neurodivergent conditions offers singular challenges which can lead to poor emotional and psychological outcomes for the parent, as well as affecting the family (MacKenzie, 2021). For mothers in my sample, more effective use of time led to positive affect, goal achievement, and well-being, facilitating greater social connections,

which generally resulted in greater support, capacity, and happiness. These outcomes support the results of prior research by Okada and Hoch (2004), Scholer and Higgins (2012), and Pfeffer and Carney (2018). Notwithstanding this, time is a resource the mothers in my sample struggled to allocate effectively, which could limit goal achievement. Its temporal capacity is acknowledged in regulatory mode through its contribution to goal achievement (Kruglanski et al., 2016) and in COR theory it is considered essential for resource protection and generation (Bell et al., 2020; Neveu et al., 2023).

My findings underscore the importance of time as a key factor in resilience, coping, self-efficacy, and satisfaction. However, it is a resource whose successful use requires control mechanisms such as routines, multi-tasking, prioritising, flexibility, and other time management techniques. Mothers spoke of their strict routines to help them with their time management. Others had learned to understand and accept their limitations, explaining that trying to achieve all they needed to accomplish was too stressful, and this had led them to say when they could not cope. Effective time management can maximise its use, reduce stress, and support fulfilment, satisfaction, and well-being. Training, coaching, and mentoring on the concept of time would help parents to acknowledge and accept their limitations while optimising time use through learned time management techniques and mechanisms.

My findings in RQ4 also highlight the importance of allowing mothers time for their own mental well-being to help build resilience. My findings suggested that supportive relationships were important for the mothers to help effective functioning, self-efficacy, well-being, and hope, endorsing work by Halstead et al. (2018). Helping parents understand the importance of personal well-being reinforces the need for its inclusion in any support package offered to mothers caring for neurodivergent children because of its contribution to parental resilience and the development of coping techniques. Previous interventions for parents caring for children with developmental disabilities have tended to focus on improving child behaviours rather than improving parental adjustments, efficacy, satisfaction, or relationships (Tellegen and Saunders, 2013; Skotarczak and Lee, 2015).

Data from the mothers in my sample demonstrated how they valued not just the empathy, acceptance, and emotional support from the people in their networks, but also the exchange of ideas and knowledge, as they perceived this empowered them. This reflects recent research, including a study on autism by Battanta et al. (2024) which highlighted the need for support, particularly from other caregivers. Similar findings were reported by Soltanian et al. (2022) studying mothers providing long-term care for children with epilepsy Soltanian et al. (2022) noted the value of social support by the family, friends and society to improve self-care. Zuurmond (2019) studying cerebral palsy published similar findings. Support, and positive awareness from others have been identified as pivotal parental needs (Reddy et al., 2019), which echoes comments made by mothers in my study, who valued opportunities to share thoughts and ideas, and offer and acquire guidance and knowledge within the safety of their networks.

The importance of other people's perceptions, understanding and acceptance, linked to social support, have been identified as more important predictors of parental psychological problems than child-focused variables (Falk et al. 2014). For mothers in my study, social networks provided opportunities to talk about their struggles and seek comfort, in a stigma-free environment through shared experiences and empathy for one-another. This supports similar findings in studies of children with disabilities and chronic illnesses (e.g. Lancaster et al., 2023). In addition to the psychosocial benefits of social networks, mothers in my sample used their networks to collect information and ideas about their children's conditions and better understand how to handle their unique needs. Parents of children with chronic illnesses require more support than many other parents. To lessen their anxiety, emotional distress, and psychological stress, parents of children with diabetes have recognised the need for assistance with not just social, practical, financial, and psychological support, but also education about their children's conditions and how to support their own wellbeing (Khalili et al. 2025).

Personal networks and the connections they brought, supported the transfer of knowledge to and from the mothers in my study. Research has consistently identified caregiver frustration about unmet information needs (Dalmer, 2020; Weissheimer et al., 2020) and found information work (Toms, 2019) to be an onerous but necessary element of parenting

(Laurin and Anderson, 2024). Mothers in my sample found it difficult to know how best to address the care and developmental needs of their children because they struggled to understand their options, and the possible future for themselves and their children. Information and advice were invariably sought from a mix of personal and online networks. Mothers commented positively on the value of exchanging information and practical advice, particularly when navigating challenges related to advocating for their children. They needed support, knowledge and information, which they were always happy to share with others. The search for information appeared to be consistent, taking up mothers' time and focusing their attention whenever they could create the capacity.

Laurin and Andersson (2024) explain the coordination and communication challenges in Sweden's care-chain for neurodiverse children. They, like mothers in my study, found that the time needed to prepare information, navigating the processes, the emotional demands of sharing it, and mediating with institutional providers to advocate for their children, created stressors. A recent study on parents caring for children with autism (Battanta et al, 2024) found that most parents experienced a challenging, protracted and exacting diagnostic process, and needed follow-up and more support post-diagnosis. Battanta et al., (2024) also reported their participants having significant financial challenges.

Larasati (2020) associated mothers' knowledge with their education as facilitators to developing skills to help their children. For the mothers in my sample, knowledge appeared to be linked more to their ability to learn about and understand the myriads of information required to advocate for their children, which generally came from their capacity to find and rationalise information from diverse sources. As was the case for the mothers in my sample, Reddy et al. (2019) noted significant challenges for parents coping with autism spectrum disorder, due to poor guidance from professionals, lengthy diagnostic and decision-making processes, reduced understanding, and family stigma. Research suggests that these facets may be addressed through support packages designed to meet parents' individual needs (Derguy et al., 2015).

Recent support interventions for parents caring for children with neurodiversity and special needs have led to the development of programs that prioritise families (McConkey et al., 2023). Successful examples have been community, and home-based (Zuurmond, 2019;

Mullan et al., 2021), utilising system-based approaches (Guralnick, 2023). The focus is on early intervention to enhance parental confidence and ability, through better information, knowledge, and community and social connections, alongside child development initiatives (Amsbary and Able, 2023). These interventions also strive to promote parental mental and emotional well-being and foster a sense of hope through self-development, empowerment, and self-confidence (McConkey et al., 2023). Furthermore, there is increasing emphasis on mindfulness- and compassion-based interventions to support parental resilience through adaptive stress appraisal and coping (Cousineau et al., 2019). Prior studies have also concentrated on mindfulness as a capacity for self-regulation (Isbel and Mahar, 2015; Li et al., 2024; Yesilkaya et al., 2024).

COR has been proposed as a framework to explain how mindfulness may support motivation in work settings (Kroon et al., 2015), which is likely to be relevant to mothers caring for neurodivergent children. Reina and Kudesia (2020) posited that people's mindfulness is not fixed or stable but arises from the individual and their situation. This suggests that people would benefit from support as-and-when their situations change.

Conceptually, mindfulness can be considered a versatile intrinsic personal resource to support resilience and facilitate the protection and generation of other resources such as confidence, self-efficacy, and optimism, as well as task engagement (Xanthopoulou et al., 2009). These three resources support resiliency and the capacity to adapt to change (Hobfoll et al., 2003) and can contribute to personal goal achievement (Hobfoll, 1989). Resources also contribute to perceived self-identity and social status, thereby influencing an individual's hope or despair (Hobfoll et al., 2003). Ultimately, mindful people perceive their life free from judgement, assessment, reflection, or scrutiny, leaving them less open to the negative feelings associated with resource loss or limited resource gain (Kroon et al., 2015). Mothers in my study who demonstrated these capacities were more resilient and coped better. This creates a strong argument for mindfulness support to be included in any support initiative.

The findings for RQ5 propose four key capabilities and capacities that mothers caring for neurodivergent children benefit from. These are mindfulness, time, knowledge, and compassion (encompassing self-compassion and compassion for others). These

capabilities and capacities are derived from the most strained resources for my sample and are recognised in RQ2. It is proposed that helping mothers bolster these resources would be most beneficial and should be included in support initiatives.

A schematic showing these four key capabilities and capacities is shown in Figure 5-1. which emphasises the caregiver as the primary focus, with the mother, alongside her family, positioned at its centre. Support initiatives must develop the four primary capabilities and capacities identified in the green circle, through a focus on the six broader skills that emerged from my analysis as the most beneficial for mothers, which are identified in the yellow circle. The six broad skills detailed in the yellow circle are time-management, coping strategies, emotional regulation, compassion, social-connection skills, and knowledge, understanding and assessment skills. The six skills reflect the most strained resources of my sample identified in RQ2 (i.e., mindfulness, psychological, time, personal skills, social connection, and finance).

In Figure 5-1 the outer blue circle in the schematic identifies the goals or outcomes that represent the mother's requirements during their journey raising a neurodivergent child. These requirements are resilience in caring, parenting, self-care, living in the present, adapting, and embracing the future through learning, development, progress, and hope. These goal achievements derive from comments made by the mothers identifying what was helpful to them. They are facilitated by the mothers' collective skills, particularly those identified in the yellow circle. External to the coloured circles, situational demands and interactions that affect and result from mothers are identified and linked bidirectionally to their resilience objectives. These demands and interactions include social connections, the child's condition and behaviour, family function, support, time availability, life situation and management, institutional involvement and interaction, and the mother's functioning and health.

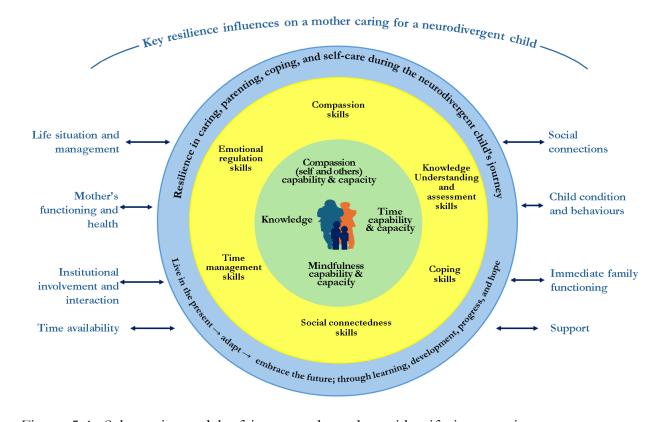


Figure 5-1: Schematic model of issues and needs to identify interventions to support mothers caring for neurodivergent children (author devised)

Mothers in my sample experienced stressors that affected their resilience and coping capacity to varying degrees. COR theory posits that resource preservation and generation is essential in the presence of stressors to prevent further resource depletion and for effective post-stressor interventions (Westman et al., 2004). The concept of increasing resources to develop and strengthen resource reservoirs is crucial for mothers to protect against new stressors, promote well-being, and maintain and develop resilience. The findings from my study linked locomotor orientation to individuals with more adequate resource situations, suggesting that interventions need to be framed with the principles of COR and regulatory mode in mind. Interventions should therefore aim to prevent resource loss but also target resource augmentation and conservation when losses begin (Hobfoll et al., 2003; Ren et al., 2023).

Recent findings on work-family conflict suggests that individuals have inherent stability in personal resources which limits meso-term loss spirals (Ford et al., 2023), reinforcing the concept of preventing resource loss to support immediate and future coping.

Notwithstanding this, research suggests that interventions should be established sooner, rather than later.

Developing support interventions

Support interventions need to help mothers, and more broadly, parents, with their time management, knowledge acquisition, compassion, and mindfulness. In line with Darc'y et al. (2021), any approach needs to be provided in a supportive client-centred social setting, efficiently coordinated, holistic, personalised, and stress-free. Interventions must meet the needs of those using the service, rather than those running it, as recent studies note difficulties incorporating interventions into daily life, and uneasiness in adopting intervention strategies (Amsbary and Able, 2023).

Ideally, interventions should be implemented and coordinated through government initiatives with action at the macrosystemic level (Bronfenbrenner, 1977). However, there is little to suggest that this is likely to happen near-term in the United Kingdom, where National Health Service systems may exist for only 1% of the neurodivergent population (Rethinking Child Neurodiversity, 2024). Funding restrictions and a limited capacity to address the problem nationally suggest that initiatives will need to be developed at the exosystemic level (Bronfenbrenner, 1977) by local and health authority actions (Integrated Care Boards in the case of the United Kingdom), or more likely, through charitable initiatives.

Recent literature provides guidance on what a successful intervention template may look like. Schemes must be delivered promptly once conditions are diagnosed or suspected, to secure the benefits of early support (Amsbary and Able, 2023). Support must fit the family's microsystems, ethics, and preferences, and this is best achieved through flexible approaches to advice, education, training, mentoring, and coaching to meet individual needs (Amsbary and Able, 2023). Families are experts in their children's lives (Cuenca-Sanchez et al., 2024), and adopting a tailored parent led approach allows them to play a central role in decisions about intervention strategies that can best meet their situations and priorities (Amsbary and Able, 2023).

Effective family-centred interventions for parents of children with disabilities are commonly home-based or integrated with local provisions (Mullan et al., 2021; Guralnick, 2023; McConkey et al., 2023). McConkey et al. (2023) reported on outcomes of The Brighter Futures Project (BFP) in rural Northern Ireland; a 12-month, family-centred support service funded by the National Lottery, based on home-visits and phone checkins. The project agreed and developed targets in partnership with the parents, which were kept under review. The approach helped whole-family functioning and recognised the need for parents to focus on their other children and their own self-care, and this was made possible during periods when their children who had intellectual and developmental difficulties were involved elsewhere in community activities.

Parents in the BFP were given practical advice and became better-informed. This was achieved through self-development, improved self-confidence, and increased capacity for self-advocacy and support-seeking, partly through greater understanding of their child's condition. Parents valued connecting with their peers through project-led opportunities, and appreciated the emotional support provided by other parents. One social worker commented that the support allowed them as parents, to develop resilience, which helped them build their own resources. The emotional support provided through the project was particularly valued, as it helped parents cope, increased their well-being, and gave them hope and knowledge on how to care for their mental health.

McConkey et al. (2023) also reported benefits from greater community connections and involvement, and with advice and information available through the project, which resulted in parents becoming more connected with their peers locally. This led to peer-peer advice, information sharing, practical support, and connections with other organisations, and initiatives, that could provide help. A key to these outcomes was the committed, knowledgeable, reliable, and supportive project staff, who were sympathetic, understanding, and willing to listen and take action to support the parents.

McConkey et al. (2023) found that some families would have benefited from longer-term support than the schemes scheduled 12-months. This could generally be achieved, since parents routinely moved on to self-help groups, which allowed families with greater need to remain involved within the main support initiative. The use of step-down support

provided a valuable contribution by creating a developed and extended network. The inclusion of parents with pre-diagnosed children in the project was also important because it can take many years to obtain a diagnosis, during which time the parents can experience the same, and potentially greater challenges than they do following diagnosis. The BFP mirrors positive results from similar initiatives of brief, individualised parenting programmes, often in resource-poor settings (Manohar et al., 2019; Tellegen and Saunders, 2014; Zand et al., 2018; Zuurmond et al., 2018).

The study by Zuurmond et al. (2018) of a 12-month programme provided by local support groups in Ghana demonstrated a relatively straightforward intervention. Facilitators took a one-week course to provide them with the basic knowledge and skills needed to support parents. The study found significant improvements in caregivers' knowledge of their child's condition, with improved critical thinking, problem solving, and benefits to personal well-being, along with high levels of peer support within their groups, resulting in the development of caregiver hope.

Other studies have identified effective approaches to help parents cope, create resilience, and deal with stressors through cognitive behavioural group therapy (CBGT). CBGT is a psychological intervention for improving mental health (Ecclestone et al., 2015), and even with relatively short intervention periods it can have positive psychological effects on mothers of children with autism, reducing their distress and improving their coping skills towards stressors (Izadi-Mazidi et al., 2015). Iadarola et al. (2018) found that relatively straightforward parent training (PT) can be effective in reducing disruptive child behaviour, increasing parental competence, and decreasing stress and strain. PT and CBGT should be useful components of interventions to support mothers caring for neurodivergent children.

My findings identified mindfulness and compassion as two of the key capacities and capabilities for mothers caring for neurodivergent children. Self-compassion is positively associated with adaptive emotion regulation and mental health (Inwood and Ferrari, 2018). Mindfulness interventions combined with compassion-focused interventions have recently been introduced, focusing on self-sympathy and sympathy towards others in the context of suffering and conflict. Compassion- and mindfulness-based interventions vary, but are

reported to develop coping capacities, resilience, adaptive stress appraisal, and emotion regulation in parents caring for children with chronic conditions, including neurodevelopmental conditions (Cousineau et al., 2019; Kemp, 2024). Threeboom et al. (2017) found that coaching led to positive emotions and self-efficacy, which supported adaptive strategies through the broaden and build concept. Parents need the capacity to respond to their children's needs despite emotional depletion, and appropriate interventions can support this.

Mothers in my study coped better and were more resilient when they engaged positively with their lives, accepted the limitations of their situation, and understood and accepted the difficulties faced by those around them. While they continued to face challenges, the mothers appeared more able to deal with the stressors that those challenges brought and focus more sympathetically on themselves and their children. Wei et al. (2021) researching the broaden and build mechanism highlighted the complementary impacts of positive emotions such as gratitude and positive attachments in creating positive spirals that enhance well-being. Positive engagement with life and acceptance of limitations led to the mothers in my sample becoming more optimistic about the future, giving them hope.

Interventions for mothers caring for neurodivergent children should nurture compassion, social connection, and caring. The concept of self-compassion extends care and kindness towards oneself during distress, and compassion for others addresses feelings for others, with the willingness to understand and relieve their suffering (Goets et al., 2010). Compassion interventions can also reduce social isolation by developing a capacity for connection (Neff and Faso, 2015) and can support resource development to shield against stressors affecting health (Seppala et al., 2013). Social support is a resource that can enhance relationships, understanding, and compassion in family and non-family settings, and can reduce affiliate stigma (Kemp, 2024; Cousineau et al., 2019). The capacity to experience positive emotions and experiences from caring for children is particularly important for mothers caring for neurodivergent children and is best achieved within understanding and sympathetic communities (Cousineau et al., 2019).

My study found that mothers caring for neurodivergent children generally felt most comfortable with peer-parents who faced similar uncertainties, challenging child behaviours, isolation, and stigmas. Distress, grief, frustration, and worry about the future are borne personally; however, peer-support can provide the opportunity to share problems with others in similar situations, who use different approaches to addressing their issues. Associating with others who have similar experiences, within a safe, sympathetic community, also supports contact with others to develop supportive networks for practical and emotional help.

Mothers consistently talked about not having the time to do everything they needed to. Managing time, and approaches to its use, can be improved through advice, education, and contact with peer-parents experiencing similar life experiences. The findings from my sample demonstrated that perceived control over time positively influenced distress, making time an important resource for individuals' resilience (Forster et al., 2023 Schilbach et al., 2023). Findings further confirmed that time management was a vital competence and capacity for mothers to have when caring for neurodivergent children. Managing time, and how best to use it, makes it an essential component of any support initiative.

Mothers in my sample struggled to obtain information to help them care for, and advocate on behalf of their children. Information work (Laurin and Andersson, 2024) is a vital component of neurodivergent childcare, but caregiver dissatisfaction with unmet information needs is common (Dalmer, 2020; Weissheimer et al., 2020). Parents require, and search for information on diverse issues to make choices in multiple domains for their children (Lacelle-Webster et al., 2018; Mansour, 2021; Weissheimer et al., 2020). Information could be effectively delivered and made available through a parent support initiative and combined with access to intelligence provided through peer support by other parents attending the initiative. Comments from the mothers in my sample demonstrated that they valued helping other parents with neurodivergent children, formally and informally, as it gave them greater purpose, perceived self-worth, and self-efficacy. Support is also a key element of compassion for others, and it helped mothers in my sample relate to and support those around them. Information develops knowledge, and the need for knowledge for the mothers in my sample was significant on a diverse range of topics. Knowledge could be effectively provided through an organised support initiative and network.

Pulling together the strands discussed in this chapter, the intervention proposed acknowledges the importance in COR theory, of the retention, protection, and acquisition of resources to cope with stressors and challenges, achieve goals, and develop resilience (Hobfoll, 1989, 2001, 2012; Radford, 2024). It also recognises the role of self-regulation in developing strengths such as emotional self-efficacy and psychological resilience in reconciling stress and anxiety (Li and Xie, 2022). The two psychological frameworks establish the theoretical base of the proposal to help support mothers' resilience and enhance their coping capacities.

My proposal puts forward conceptual initiatives which would be provided locally to groups of parents caring for neurodivergent children. Interventions must be system-based providing early intervention, but their design and implementation must be individualised and developed collaboratively with the parents involved to limit barriers to participation. Based on my findings, people's life situations can be improved and are not predestined, which supports the relevance of intervention initiatives. In my proposed support intervention, enablement and enhancement of four key capabilities and capacities for mothers, and by extension, their families, are the overriding capabilities and capacities of knowledge, time, compassion, and mindfulness. These four capabilities and capacities rely on the development of six skills: knowledge, understanding and assessment, time management, compassion, social connectedness, emotional regulation and coping, noting that coping incorporates elements of compassion, emotion regulation, and knowledge, understanding and assessment skills. These facets should be key foci of any intervention initiatives.

Conceptually, the initiatives should be available on a 'drop-in' basis, with skills-support available each day, but specialist elements such as CBGT available by prior arrangements as these inputs will require external input; however, compassion-focused therapies and CBGT can be provided virtually. These therapies can contribute to compassion and mindfulness, improve emotional regulation and well-being, reduce stress, provide hope, and psychological support. Mindfulness and compassion are also important contributors to compassion and social connections. Other specialist inputs, such as financial and legal advice, could also be made available through prior arrangements.

Support to build parental skills should include advice and education for knowledge and understanding of neurodiverse conditions, and assistance for interceding with institutional providers to help parents navigate processes, and advocate for their children. This support could, in part, be provided by peer-parents who may be experienced in or more capable of navigating often complex systems and procedures. Knowledge development and understanding will build parental confidence and ability, support self-development, empowerment, and ultimately resilience and coping.

Advice and parent training must facilitate an understanding of the importance of time use and techniques for its management and coordination. Again, this education could draw on peer-parents who are already able to effectively manage their time. Effective use of time can also contribute to emotional regulation, goal achievement, coping, and resilience. The involvement of, and contribution from peer-parents, is vital not just to expand the capacity of the intervention initiative, but to tap into the extensive knowledge and experience that parents have from caring for neurodivergent children. This knowledge can be passed on in a safe, judgment-free environment, where new social connections can be made, and an array of practical and emotional advice can be taken and given.

Finally, mothers in my sample mentioned the benefits they had or would like to have had from access to a drop-in centre that allowed them to have a quiet space for themselves. In this space, they could work, or relax, while their neurodiverse children were supported by competent care-staff, either nearby, or in well-devised community activities. Other mothers wished for access to people who did not judge them or their children and were knowledgeable and willing to provide help and support. Many mothers were keen to have the opportunity to meet and socialise with their peer-parents in an appropriate environment to talk about their children, themselves, and their problems, or to exchange knowledge, information, and experiences, knowing that their children were safe, cared for, and accessible. These are principles, alongside my RQ findings, that set the scene for my proposed interventions.

Summary of chapter

I summarise this chapter by emphasising how my findings contribute to the existing knowledge in the following areas.

- Connection between COR theory and regulatory mode
- COR theory, and mothers caring for neurodivergent children
- Resource caravans
- Resource passageways
- Time, its use, control, and impacts
- Social support

Connection between COR theory and regulatory mode

Previous research on Conservation of Resources (COR) theory has not adequately considered an individual's regulatory mode orientation, and vice versa. Although there is limited research connecting regulatory mode orientation with COR theory, the potential links between these concepts appear evident. COR research generally conceptualises selfregulation as a mechanism for resource control, but has failed to be explicit, or follow-up on nascent associations. Halbesleben et al. (2014) proposed that new resources might enhance goal achievement more effectively than existing ones, yet this proposition has not been further explored. Tesi (2021) examined the regulatory mode within the context of the job demands-resources (JD-R) model, highlighting the significance of job and personal resources in achieving goals, but did not expand on this theme. Diestel (2022) investigated the demands of self-control in managing job demands that necessitate self-regulation, while Gerpott et al. (2022) suggested that self-regulation depletes regulatory resources, resulting in ego depletion. However, these last two areas have not been further investigated. The existing literature also indicates that an individual's resource situation may substantially influence their approach to goal pursuit and achievement (Jansen et al., 2022), as well as affect resource protection and generation. This line of inquiry has not advanced.

I believe it is plausible that the inability to protect, create, or sustain resources is associated with an individual's assessor or locomotor orientation. Furthermore, the omission of locomotion and assessment orientation in COR research may overlook critical factors

influenced by psychological frameworks. I consider that it is important for future research to understand these potential links, their impact, and implications.

Regulatory mode research shows that locomotors benefit from maximising movement per unit of time and that locomotion focus is crucial for effective goal management (Kruglanski et al., 2016). This appears to align with COR theory's emphasis on resource protection and generation to prevent loss, recover from loss, and gain resources (COR Principle 2) (Hobfoll, 2018). Locomotion is also positively associated with perceived social support, optimism, self-esteem, emotion, hope, and engagement in positive activities (Jansen et al., 2022), which COR literature identifies as resources for well-being and coping (Alarcon et al., 2011; Ouweneel et al., 2011).

While regulatory mode typically focuses on either assessment or locomotion (Mathmann and Chylinski, 2022), my findings also identify an association between a mixed assessment and locomotion orientation and inadequately resourced caravans. Previous research suggests that individuals with assessor orientations are likely to have more limited resources and diminished capacity to achieve goals (Amato et al., 2019; Choy and Chung, 2018; De Carlo, 2014; Jansen et al., 2022). The association I noted may be rationalised by the concept of complementarity (Pierro et al., 2018), where individuals with limited resources benefit more from combining assessor and locomotor orientations rather than relying on only one. This aligns with previous studies showing how assessment and locomotion orientations work together to address higher-level goals (Chernikova et al., 2016; Mauro et al., 2009; Pierro et al., 2018). Research on regulatory modes in social media sharing also indicates that high construal levels (viewing situations broadly and abstractly) can facilitate the integration and interdependence of these two orientations (Pham et al., 2023). This arises from regulatory mode complementarity, fostering regulatory fit or balance (Avnet and Higgins, 2003; Kruglanski et al., 2000; Pham et al., 2023).

COR and mothers caring for neurodivergent children

Studies on mothers caring for neurodivergent children within either framework are lacking. My findings directly contribute to COR theory by identifying key personal resources for these mothers: financial, social support, time, health, cognitive, psychological, mindfulness, and personal skills, and immediate family support. These nine resources align with those

identified in COR literature for parents of children with long-term illnesses, which include financial, personal skills, time management, health, and psychological well-being (D'Arcy et al., 2021; Hauge et al., 2015; Heymann and Earle, 1999; Heymann et al., 2010; Marfo, 2024). Social and community resources from family members and others have also been established as providing support to parents (Babatunde and Akintola, 2023; Paintal and Aguayo, 2016; Payne et al., 2012; Shattnawi et al., 2021; Shaw et al., 2017). COR theory suggests that mindfulness enhances work motivation and performance (Hyland et al., 2015; Kroon et al., 2015), which may be equated to caregiving motivation in mothers of neurodivergent children.

My analysis identified five distinct combinations of mothers' key resources that varied in makeup and quality. These resource collections depicted the resource caravans of key resources for each mother and enabled grouping based on the resource strength. With no apparent prior research on mothers caring for neurodivergent children, these resource caravans extend the existing knowledge within COR theory.

Resource caravans

The resource caravans discussed in the last section help identify the strength of the nine key resources for both the stronger and poorly resourced mothers in my sample. My findings suggest that mothers in the two weakest caravans generally valued assistance with their psychological, time, mindfulness, financial, personal skills, social, and immediate family support resources. Mothers in stronger caravans also benefited from support with time, psychological, financial, and mindfulness resources, making these four particularly important. Identifying key resources for mothers caring for neurodivergent children, a seemingly unresearched group in COR, extends COR theory.

Resource passageways

Resource passageways help explain how individuals build and use resources to develop resilience and manage stress (Chen et al., 2015; Hobfoll et al., 2018). Resource passageways develop during people's lives through experiences, interactions, and opportunities at the individual, micro, meso, exo, and macrosystem levels (Bronfenbrenner, 1977), and they affect and influence resource use, maintenance, and accumulation (Hobfoll, 2012). Opportunities and options resulting from resource passageways vary and can provide

cumulative advantages or disadvantages in resource use, maintenance, and generation throughout an individual's life (Dannefer, 2003; Elder, 1998; Johansson et al., 2007; O'Rand, 2009; Ye, 2024).

Despite facing similar challenges, the mothers in my sample exhibited varying resilience and coping capacities due to differences in their personal resources. This variance was partly linked to their past experiences, which influenced the development and evolution of their resources through their resource passageways. This aligns with Hobfoll (2011, 2012) and Kaur et al. (2024), who recognise that passageways evolve through the impact of people, agencies, and life-course opportunities or constraints. Consequently, individuals benefit from these passageways through support in resource development and maintenance, or suffer from risks to, or depletion of resources (Dannefer, 2003; Elder, 1998; Johansson et al., 2007; O'Rand, 2009; Ye, 2024). My findings extend the concept of resource passageways by including mothers caring for neurodivergent children, a previously unexamined group.

Challenging traditional cumulative advantage and disadvantage concepts, within resource passageways, my insights indicate that while a more advantaged and supportive childhood could, and was likely, to lead to a more positive later life, it is also evident that a restricted earlier life does not irrevocably lead to a challenged later life. My finding that life-course trajectories can change for the better may support evolving literature (Dai and Li, 2023, Vilhena et al., 2019). My analysis showed that the mothers had influenced, affected, and changed their lives for the better and that these changes appeared to be substantive rather than situational.

I identified four resource passageways for mothers caring for neurodivergent children that were previously unrecognised within COR theory. The concept of empowering, limiting, and restricting resource passageways are recognisable, if not explicit, in the existing literature, but the concept of opening passageways appears to add to and enhance existing research on resource passageways.

By establishing associations between regulatory mode and COR, my research also suggests that resource passageways may influence not only individuals' resource caravans but also their regulatory mode orientations, reinforcing the possibility of links between the two

frameworks. This study contributes to the literature, as no prior research has examined regulatory modes and resource passageways.

Time, its use, control, and impacts

My findings support previous research on time use, how people value time, and the effects of poor time use.

Time pressure was a significant challenge for mothers in this study. Insufficient time could physically and mentally strain them, limiting task completion. This finding aligns with recent research indicating that time pressure depletes energy and resources, causing increased fatigue, emotional exhaustion, impatience, and psychological distress (Mühlenmeier et al., 2022; Pfeffer and Carney, 2018; Schilbach et al., 2023). This suggests that these findings can be extended to a previously unexplored cohort in COR theory.

The mothers in my sample who were most effective in managing their time exhibited a locomotion orientation, corroborating previous research such as Lee-Yoon and Whillans (2019), who found that high locomotors optimise their time, treating it as a limited resource. This also aligns with Pierro et al. (2013), who identified multitasking as a common behaviour among locomotors to enhance time management by minimising the time required for goal achievement. Techniques for time management identified in my study included taking more control, multitasking, prioritising, flexible time use, routines, and focusing on short-term tasks. The latter was common among the mothers, who often exchanged longer-term rewards for more immediate, albeit less valuable, outcomes - an example of temporal discounting (Lowenstein et al., 2003). For mothers with locomotor orientations, the desire for goal achievement seemed to increase the value of near-term over long-term rewards, leading them to accept lower-value short-term gains, as suggested by Hobfoll et al. (1989). My findings do not support Lin et al.'s (2019) study finding that people prefer long-term resource investments for greater future returns. This discrepancy may be due to the unique challenges faced by mothers of neurodivergent children or mothers generally dealing with constant time constraints and difficult prioritisation decisions.

Research indicates that as time becomes more significant for an individual, their self-focus increases, weakening social and prosocial behaviours and jeopardising personal well-being

(Lee-Yoon and Whillans, 2019). Mothers in my study, who faced greater time constraints, appeared more self-focused, leading to diminished social and prosocial activities, higher stress levels, and limited coping mechanisms. The causal relationships between these factors were unclear from the data developed from the mother's interviews. It is possible that their lack of self-focus might have stemmed from increased stress, time challenges, or reduced coping ability.

The mothers in my sample fit the five derivations of time related to locomotion proposed by Kruglanski et al. (2016), who suggested that locomotors, as opposed to assessors, use time more efficiently and perceive more successful use of time. My findings extend these derivations to mothers caring for neurodiverse children, and potentially to parents of children and adults with significant long-term needs.

Social support

My analysis revealed that support from others was crucial for mothers in my study, who frequently depended on advice, support, and guidance from family, friends, colleagues, and others. Despite some difficulties in accessing social support, it provided significant practical guidance and resources to overcome challenges and achieve key goals. This finding aligns with previous research on the importance of social support (Cohen and MacKay, 1984; Feeney and Collins, 2014). Qi and To, (2025) advocate the promotion of social support networks to ease caregiving burdens.

COR research highlights the importance of work and colleague attachment as a resource for mediating resource loss, supporting resource gain, and mitigating negative outcomes from stressors (Karatepe, 2015; McTiernan et al., 2016). Routine interactions, and support during times of need from diverse social networks enhanced the mothers' sense of connection and acceptance and reduced their perceived stigma. Baumeister and Leary (2017) emphasised the significance of belonging and acceptance, noting that failure to belong can lead to misunderstandings, social exclusion, and loss of support (Leary, 2005). This was evident among those mothers in my study with limited social connections. Conversely, reassurance and friendship positively and significantly affected mothers who sought and gained support to address their negative experiences, worries, and anxiety. This finding aligns with those of Kane et al. (2012) and Marigold et al. (2014; Qi and To, 2025),

who found that individuals turn to close others for support in dealing with stressors and negative moods.

COR theory (Hobfoll, 2011) and self-regulation (Zee and Kumashiro, 2019) emphasise the importance of an individual's social context. The positive aspects of constructive social support are linked to engagement in locomotors, who are more likely than assessors to welcome support from close others, leading to increased engagement and goal pursuit (Zee and Kumashiro, 2019). The mothers in my study with stronger social connections better managed their routine stressors and daily challenges. Hobfoll (2011) argued that individuals are embedded within the family, tribe, and social context, highlighting the significance of social connections, as was evident from the mothers in my study. Higher locomotors benefit more from close social support, which enhances goal engagement (Zee and Kumashiro, 2019). This self-regulatory link is pertinent to mothers caring for neurodivergent children in my study.

A notable finding of my analysis was that mothers utilised various interconnected resources in their lives to build resilience and cope. These resources encompassed friends, family, colleagues, customers, clients, and other routine and occasional associations. The mothers in my sample valued their social, work, and family connections, drawing positive effects from different life aspects to strengthen their resilience and coping capacity. This aligns with the crossover model (Chen et al., 2015; Sha and Huang, 2024) and the broaden-and-build mechanism (Frederickson, 1998, 2000), commonly referenced in COR research, but not previously explored in the context of mothers caring for neurodivergent children.

Crossover involves the transfer of resources, emotions, and experiences among individuals within a social context. The crossover model includes both negative and positive effects, but can promote engagement by transferring resources, leading to resilience, flexibility, and better health (Chen et al., 2015; Sha and Huang, 2024). The broaden-and-build mechanism (Fredrickson, 1998, 2000) fosters positive emotions that indicate well-being, enhance mood, and predict future well-being (Fredrickson and Joiner, 2002), potentially improving coping strategies and resilience (Burns et al., 2008). The concepts of crossover and broaden-and-build appear relevant to parents caring for neurodivergent children, and the link to mothers caring for neurodivergent children extends these two constructs to a new area of study.

Conclusion

This chapter examines how my findings challenge and expand existing knowledge. The literature review revealed a significant absence of studies integrating COR theory with regulatory mode orientations of assessment or locomotion. This gap highlights the lack of research connecting regulatory modes with personal resources and an individual's resource situation. Additionally, there is a scarcity of studies exploring the relationship between COR or regulatory mode and mothers of neurodivergent children. The findings identified links between locomotion orientation and well-resourced caravans, and a mix of assessment and locomotion with poorly resourced caravans. Asserting that assessment and locomotion operate together and complement each other in mothers caring for neurodivergent children enhances regulatory mode theory (Kruglanski et al., 2000). Additionally, my findings contribute to COR theory by identifying key personal resources for the cohort of this study and developing five resource caravans for the mothers. Furthermore, the findings contribute to the regulatory mode construct and COR theory by incorporating mothers caring for neurodiverse children into these psychological frameworks.

Resource distribution among the mothers in my sample was linked to their past circumstances, supporting previous research on resource passageways (Hobfoll, 2011; Kaur et al., 2024). However, while an advantaged and supportive childhood is acknowledged as leading to a more positive later life, my findings identified that a limited early life does not necessarily result in a challenged later life, extending the existing research. Additionally, I identified new conceptual passageways that have not been previously established, either for mothers of neurodivergent children or within COR theory. My research indicates that resource passageways may affect both an individual's resource levels and regulatory mode orientation, suggesting a connection between the two frameworks, thus contributing to the existing literature on these psychological models.

My findings corroborate prior research on time use, how people value time, and the adverse effects of poor time management (Amato et al., 2014; Amato et al., 2019; Kruglanski et al., 2016; Tao and Jing, 2023; Whillans and Dunn, 2019). They also align with studies on temporal discounting (Lowenstein et al., 2003; Villmoare et al., 2023) but may not fully support Lin et al.'s (2019) COR theory proposition, particularly for mothers of neurodiverse children, regarding a long-term approach to resource investments for greater

future returns. My time subtheme acknowledges the crossover model (Chen et al., 2015; Sha and Huang, 2024), and broaden and build mechanisms (Frederickson, 1998, 2000) for these mothers.

My findings validate the significance of work and colleague attachment (McTiernan et al., 2016) and the importance of belonging and acceptance (Baumeister and Leary, 2017). Additionally, they emphasise the high value placed on practical help and advice, supporting Feeney and Collins (2014).

6 Contribution to knowledge and practice

This chapter provides a comprehensive synthesis of my research by integrating my research questions, data analysis, and outcomes. The chapter underscores the contributions to theory and knowledge and proposes areas for future investigation to build on my initial findings. Limitations are discussed, and I offer practical suggestions for establishing a framework for future support initiatives for mothers caring for their neurodivergent children, using conservation of resources (COR) theory and self-regulation. I argue that implementing the intervention initiatives proposed in this study can significantly improve the lives of individuals facing extreme daily challenges in caring for themselves and their children. Moreover, I suggest that these initiatives could potentially benefit a wider audience, including employers and those in care roles supporting others.

Research questions

Figure 1-1 presents the research questions developed from the research gaps.

Contribution to knowledge

This study aimed to formulate initiatives to support mothers of neurodivergent children through COR theory, alongside assessment and locomotion within regulatory mode. The literature review revealed the absence of studies integrating COR theory with regulatory mode orientations of assessment or locomotion. This absence of literature linking regulatory modes with personal resources and an individual's resource situation identifies a significant gap. There is also a lack of studies examining the relationship between COR or regulatory mode and the mothers of neurodivergent children. While prior research suggests potential applications of each theory to this demographic, a gap remains regarding their combined application in supporting these mothers.

Development of a support framework

Although prior literature in COR and regulatory mode does not appear to have considered this cohort of caregivers, the literature suggests that these two frameworks may be relevant to them. Relevant examples include, for example, the negative effects of poor time use (Whillans and Dunn, 2019) the importance of work and colleague attachments (McTiernan et al. 2016), the importance of belonging and acceptance (Baumeister and Leary, 2017), and the value of practical help and advice (Feeney and Collins, 2014).

This study established that COR theory and regulatory mode can be used as the basis for establishing a practical and effective framework to support mothers caring for neurodivergent children. The outcomes of the final research question provide recommendations for developing this support. As this appears to be a new application for COR theory and regulatory mode, the development of a proposed framework to support such mothers presents a particularly significant and valuable contribution, extending the application of both frameworks, and broadening the scope of how the two can be applied. This contribution is enhanced by its practical value, relevance, and potential applicability to other cohorts of mothers, parents, other caregivers, and potentially other agencies, and employers.

Linking conservation of resources theory and regulatory mode

Prior research has not linked COR and regulatory mode. The relationships between the two frameworks found in this study shed light on the existence of connections, recognising that mothers with a locomotion orientation also had well resource caravans, and those with a mixed assessment and locomotion orientation also had poor resource caravans. As neither of these relationships has been previously established, this finding extends both COR theory and regulatory mode.

The link between a mixed assessment and locomotion orientation and a poorly resourced caravan sits in contrast to what might be expected from prior literature, which suggests an assessor orientation link with a poorly resourced caravan, since assessors are prone to procrastinate, delay goal progression, and live for the moment, rather than prioritising change. I suggest that the concept of complementarity (Piero, 2018) may be behind this finding, as natural or situational assessors may draw on locomotion traits to support goal movements which may otherwise be reduced through a purely assessor orientation (e.g., Amato et al. 2019; Jansen et al. 2022). This is not unreasonable, because everyone has elements of both assessor and locomotion proclivities, although one orientation is routinely dominant (Mathmann and Chylinski, 2022). This finding supports and extends the concept of complementarity and highlights how assessor and locomotor orientations work together, in line with Pham et al. 2023.

Key resources for mothers caring for neurodivergent children

The findings of this study determine key resources and groups of stronger and weaker resources that can be used to provide practical support for parents caring for neurodivergent children. This is a new finding in COR theory and regulatory mode, and a significant and valuable extension to knowledge which can be used practically to provide support to often-challenged caregivers. Establishing nine key resources was important not only because these key resources do not appear to have been proposed previously, but also because they form the foundation for understanding the valuable skills needed by the mothers in this study. Ultimately, they help determine the key competencies and capacities that should be the focus of any support initiatives for mothers caring for neurodivergent children. It is notable that the nine key skills identified for the mothers in this study are also a focus of literature on parents caring for long-term chronically sick children.

Determining the nine key resources was important. However, identifying five distinct combinations of those resources helped to highlight which were most valuable for all mothers, regardless of whether their resource caravans were well or poorly resourced. Establishing key resources and how these resources cluster for mothers caring for neurodivergent children informs and extends COR research.

Resource passageways and life improvement

The relevance of mothers' life courses linked to their resource passageways provides insight into how life events and experiences influence their lives. The findings of this study support previous research on the passageway concept (Hobfoll, 2011, 2012; Hobfoll et al., 2018; Kaur et al., 2024). However, it also extends knowledge by establishing how resource passageways apply to mothers caring for neurodivergent children.

My analysis developed the four proposed resource passageway concepts of what I called empowering, opening, limiting, and restricting resource passageways. These do not appear to have been conceptualised previously. The suggestion of a range of resource passageways affecting current lives is not explicit in prior literature, although the concept of empowering, limiting and restricting resource passageways but may be assumed. However, the proposal that a range of trajectories exists for mothers caring for neurodivergent children does extend the resource passageway concept in COR research. The proposed

concept of an opening resource passageway is not recognisable in the literature and may therefore provide a significant extension to current research, and its applicability may be extensive. The concept highlights the importance of agency in people's lives and broadens our understanding and appreciation of the passageway concept. It also a suggests that initiatives to improve the lives of even the most challenged people is realistic, and not just aspirational.

COR and regulatory mode interrelated functioning

My findings suggest a level of integrated functionality between the frameworks of COR and regulatory mode orientations. A locomotion orientation in regulatory mode was found to be associated with strong resource reservoirs, and a connection between a mixed assessment and locomotion orientation and poorly resourced caravans was identified. These findings suggest that the two frameworks may play a joint role in supporting goal achievement, resource protection, recovery, and gain. Establishing this extends COR theory and the regulatory mode construct by contending that they may work and operate harmoniously, thus providing a significant and valuable contribution to both the psychological frameworks.

Time in COR and regulatory mode

The impact of time pressures and the ways in which individuals value and use time have been extensively considered in COR and regulatory mode literature. These findings are relevant to mothers caring for neurodivergent children, and the significance of time was confirmed in this cohort, one that has not been previously considered within either framework. Therefore, this study highlights a new study population for which time is a significant resource which needs to be carefully managed to meet competing daily demands. Beyond this, specific concepts relating to the importance of time for this cohort of mothers have been identified and explained. My findings underscore the challenges and complexities of forming, maintaining, and exploiting social networks among the mothers of neurodivergent children. They highlight the value of support for caregiving responsibilities within familial relationships and underscore the importance of supportive work environments and work colleagues in providing social connections for emotional support and respite.

Social support in COR and regulatory mode

My findings complement and extend other findings on social support and demonstrate that prior research on the two psychological frameworks is also valid for mothers caring for neurodivergent children. The value that mothers caring for such children place on social support for guidance and practical help is clear from the findings of this study, and complement for example, Feeney and Collins (2014) and McTiernan et al. (2016). The importance of belonging and acceptance in my sample was insightful, and the impact of misunderstanding, social exclusion, and loss of support from others could be significant for mothers, which resonates with previous findings (Leary, 2005). This was particularly evident in mothers whose social connections were limited, as mothers with greater social connections appeared more capable of dealing with routine stressors and coping with daily tasks and challenges. This complements the findings of Zee and Kumashiro (2019) that locomotors are more likely than assessors to welcome support from others, which, in turn, enhances goal pursuit.

The relevance of crossover and broaden-and-build

The crossover model (Bolger et al., 1989; Chen et al., 2015; Sha and Huang, 2024) and broaden-and-build mechanism (Frederickson, 1998, 2000) are routinely discussed in COR research, although they do not appear to have been previously considered in the context of mothers caring for neurodivergent children. Crossover originally described how one person's stress negatively affects another in the same social context, but significant for this research, now incorporates the transmission of positive experiences (Westman, 2013). The positive effects of both crossover and broaden-and-build can be identified in my findings, extending the relevance and potential importance of these two constructs to mothers caring for neurodivergent children. By linking COR and regulatory mode, my findings also suggest that regulatory mode may play a role in crossover and broaden-and-build.

Broaden-and-build and crossover require social and communal networks. Mothers in my sample with better networks had stronger resource reservoirs, greater resilience, and better life satisfaction, and generally coped better. They responded more positively to negative situations and stressors, were more positive, and appeared to have fewer mental health problems. Crossover and broaden-and-build contend that these complimentary effects are

likely to result from passed-on positive emotions from others, helping to build self-efficacy, and creating positive emotional spirals that improve well-being, positivity, and hope (Cohn et al., 2009; Iyer et al., 2003; Sha and Huang, 2024; Theeboom et al., 2017; Wei et al., 2021). Crossover and broaden-and-build, specifically their associations with COR theory, therefore appear relevant and important to parents caring for neurodivergent children, suggesting that my findings extend these two constructs.

Challenges to theory

The findings of this study also challenge existing theoretical and conceptual models.

Research (e.g. Hobfoll et al., 1989; Lin et al., 2019) has found that people prefer to make long-term investments to gain more valuable future rewards rather than setting short-term goals yielding lesser rewards. Indeed, pursuing less significant, more immediate rewards may conflict with the pursuit of more substantial and possibly inaccessible goals (Wenzel et al, 2024). My findings challenge this, as the norm for mothers in my sample was to focus on goals that could be achieved quickly. This difference may be specifically linked to obstacles faced by mothers caring for neurodivergent children with more extreme time challenges and difficult choices about priorities. Reinforcing this was the observation that this finding was most profound in mothers who coped less effectively with their stressors and had poorer resource caravans, resource passageways, and support from their networks.

My findings may also challenge traditional cumulative advantage and disadvantage and resource passageway assumptions while supporting emerging research suggesting that lives can be improved through evolving individuality and development. My finding of a proposed opening resource passageway highlights the importance of agency in the lives of mothers caring for neurodivergent children. Poor starts in life do not inevitably presage poor future lives, even for mothers who have experienced significant traumatic experiences, anxiety, and depression. This concept may be extended more broadly to the resource passageway construct. This challenges traditional resource passageway, and life course literature proposals that early life transitions have lasting impacts on well-being (Williams and Umberson, 2004). My findings complement the emerging literature on the Matthew effect and life course trajectories, which suggests that people's lives can be improved by evolving individuality and development (Dai and Li, 2023; Vilhena et al., 2019). These findings are also hinted at in research by Jackson and Engleman (2022),

Johnson-Lawrence et al. 2015, Lee et al. 2022). My finding potentially extends these emerging life-course findings to COR theory.

Practical application

A key output of this study is a support framework for mothers caring for neurodivergent children. The mothers in my sample had children with a mix of neurodiversity's, and most children also had comorbidities. Therefore, the findings of this study are likely to be representative of mothers who care for children under the general heading of neurodiversity, fathers, and possibly, or in part, other family members taking significant responsibility for the care of the neurodivergent children of other family members. The results of this study may therefore be applied more widely to other cohorts of caregivers in numerous environments. The variation in the children's conditions and comorbidities in my sample suggests that findings, specifically those relating to the identified capacities and capabilities, key resources, resource caravans, aspects of self-regulation, and significant factors surrounding time and social support, may be generalisable and representative of a wider cohort of caregivers. Cohorts of parent caregivers, such as those providing care for long-term sick children or those linked to protracted acute care, may benefit from the support framework derived from this study's findings. The findings could potentially extend further, for example, to adults caring for aged parents with dementia who face similar time, knowledge, and social challenges.

Additionally, current research offers little advice on practical support for caregivers in organisational settings (Doyle, 2020). Support proposals in this thesis could be embraced by larger forward-thinking employers with an eye on diversity and inclusion (D&I), the HR capacity, and drive to create support hubs for employee cohorts. In addition to supporting D&I, initiatives could assist employee retention, encourage the return to work of valuable ex-employees, and develop a more flexible and diverse workforce. Reaching out to, and adoption by the business sector may create support and acceptance of neurodiversity in the workplace, and help employees maintain their commitment and well-being by feeling valued and enabled. The concept proposed lends itself to larger organisations but could be applied to smaller progressive companies using a specific selection approach, driven by the employee cohort.

The outcome of this study has the potential to inform diverse care professionals, such as paediatric healthcare workers, care home staff for the young and old, and perhaps hospice caregivers, by helping them understand the help and knowledge needed by individuals caring for others. Specifically, understanding the four key capabilities and capacities of compassion for self and others, time management, mindfulness, and knowledge, and the associated skills noted in the findings of RQ5 (see Figure 1-1), and how to educate and support caregivers in them, could be particularly valuable.

The results of this study may provide wider social benefits by improving the inclusion and acceptance of a frequently misjudged and at times maligned cohort of mothers who can struggle to understand their own situation but are also often misunderstood by others. This study has scope to raise awareness and understanding of people working in support roles with parents of neurodivergent children, as well as employers, and charities. However, this is merely a starting point, as the findings of this study provide a platform for developing extensive practical assistance and support mechanisms. This concept is discussed further in the next chapter. The outcomes of this study might provide progressive employers with the means to understand the support needed by parents of neurodivergent children so that they can remain in or be recruited into the workforce and, more significantly, contribute more fully to industry and society.

Research limitations

This study had several limitations. The scope may have been limited by sampling issues. Although I reached out to a diverse population of parents in the United Kingdom and abroad, apart from two volunteers, my sample was all mothers caring for a mix of neurodivergent children living in England, Scotland, and Jersey. All mothers, except one, were Caucasian. The generalisability and representativeness of this study's findings may consequently be restricted. Other factors may also have limited generalisability and representativeness, such as the need for participants to be IT-capable and able to join an online MS-Teams interview. Additionally, the presence of neurodiversity or comorbidities in children relied on parent reports, meaning conditions were not verified. These factors may limit the generalisability of the findings, although the results are likely to be generalisable to mothers caring for neurodivergent children in the United Kingdom (UK).

The findings suggest that the results may, however, have wider generalisability, as much prior research suggests that the impacts of providing general long-term care for children have similar effects on parents as those noted in the mothers of this study. This argues for the wider generalisability of the results. Inevitably, however, the results are based on mothers living and raising neurodivergent children within specific institutional support systems, financial and social support mechanisms, and UK policies, which may limit their generalisability.

I assessed the sample to have reached saturation by the 16th interview but continued to interview beyond that point to develop transcripts for 19 usable participants. Despite this, additional interviews may have identified more participants with assessor and a mixed assessor and locomotion orientation, which would have helped solidify my findings by linking assessors and mixed orientations to adequate, intermediate, and inadequate resource situations. Additional participants may also have provided greater clarity on potential COR theory links to parents with assessor orientations, which my results failed to clarify.

Most related studies have concerned a specific neurodiversity, such as autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD). The volunteers for this study led to me exploring mothers of children with neurodiversity as a general condition, and just mothers, rather than parents. My focus on neurodivergence rather than specific conditions may nevertheless be valuable because my findings showed that most mothers had more than one child, often with different neurodiverse conditions, and some affected by more than one. This suggests that parents with more than one neurodivergent child rarely deal with a single neurodiversity in their children. Lang et al. (2024) and others have identified that 70% of children with autism will have one or more co-occurring neurodivergence. Many of the children in my sample also had comorbidities, many of which resulted in significant challenges and stressors for the mothers. Despite the characteristics and resulting behaviours of children differing significantly between neurodiversity's, overall, the data developed in this study did not identify notable differences resulting from the children's neurodiverse conditions regarding the general functioning, or support needs, of the mothers.

Some mothers reported being neurodivergent. This could be significant, as neurodivergent parents generally face greater struggles in life and deal with stressors differently than non-

neurodivergent parents (Dugdale et al., 2021). The existing literature on the proportion of parents with neurodiverse children who are themselves neurodiverse is limited, but Dugdale et al. (2021) suggest that it is not uncommon. Non-academic sources suggest that an association is likely (Mueller, 2024), and Pring (2023) identified parents as neurodivergent in 77% of families with a neurodivergent child. The importance of this is that ADHD behaviours can include inattention, hyperactivity, time-blindness, forgetfulness, and mind wandering. ASD behaviours include communication problems, preferences for routines, challenges with communication and social signals, social overload, and isolation. These traits and characteristics may themselves affect mothers' behaviours, resilience and coping, which, in the context of this study, could present a limitation. However, although other studies of parents caring for neurodivergent children will encounter similar issues, this limitation does not appear to be acknowledged, and it may simply be a feature rather than a limitation of all research on such parents; however, this is a potential limitation.

Despite the limitations of this study, its value should not be underestimated. Recognising the associations between the two frameworks is an important step towards developing and progressing future research. This study provides important theoretical and conceptual models and concepts and adds important findings for a new cohort of mothers caring for neurodivergent children. Developing practical support for these mothers when the number of neurodivergent children is increasing (Psychology Today, 2023), but a collective shortfall of over £91 billion funding is forecasted for special education needs and disabilities in the UK (BBC News, 2024) reinforces the importance of this research, and the need to identify initiatives to support them.

Opportunities for future research

Potential areas for future research flow from the contributions to knowledge covered in this chapter and are as follows.

- Links between regulatory mode and COR theory
- Key resources and resource clusters
- Resource passageways, and cumulative advantage and disadvantage
- Short-term focus of mothers caring for neurodiverse children
- Crossover and broaden- and-build
- Proposed interventions

Links between regulatory mode and COR

Further research is needed to validate and confirm the nine identified key resources and resource clusters that I have established. It would be valuable to understand whether a wider and larger sample of mothers, or ideally parents, identified the same or other resources as being particularly valuable. A significantly larger sample size than that used in this study is needed.

Key resources, resource clusters

My findings link locomotion orientation to stronger resource reservoirs and indicate a connection between a mix of assessment and locomotion and poorly resourced caravans. These findings suggest that the two frameworks may have a joint role in supporting goal achievement, resource protection, recovery, and gain, which are key aspects of both psychological frameworks. This contends that COR and regulatory mode can work and operate in harmony. Verifying this would be a valuable extension of knowledge. It would be useful to verify my findings on regulatory mode orientation and resource situation in a larger sample so that my nascent findings can be better understood. Understanding and establishing associations among individuals with an assessor orientation would be particularly valuable.

Resource passageways through cumulative advantage or disadvantage

My findings suggest four conceptual resource passageways linked to an individual's life course. These do not appear to have been conceptualised previously in COR theory research, and it would be useful to verify them through further studies. I highlight my proposal of an opening resource passageway concept as specifically worthy of further investigation to test and confirm my findings. Although COR studies on resource passageways do not appear to consider this concept, recent studies on cumulative advantage and disadvantage and the Matthew effect have suggested that this may occur through evolving individuality and development (Dai and Li, 2023; Vilhena, 2019). As resource passageways and cumulative advantage and disadvantage are frequently associated in research, the proposed existence of what I have called opening resource passageways

would benefit from further research to establish their validity through wider study using a larger sample base.

Short-term goal focus

The findings of this study challenge those of Hobfoll et al. (1989) and Lin et al. (2019) which found that people prefer to adopt a longer-term approach to resource investment to gain greater future returns. My findings show that most mothers caring for neurodivergent children preferred shorter-term goals. Although this observation was common, it may be relevant that the mothers in whom this was most significant, appeared to be more self-focused, had reduced social activities, and coped less well. These observations appear to complement Lee-Yoon and Whillans's (2019) findings that people sacrifice social interaction to save time or work, which can result in social isolation and unhappiness. It may therefore be the case that individuals experiencing more significant stressors without support mechanisms focus on short-term goals for purely practical reasons. It would be helpful verify this nascent finding. To verify and better understand the implications of this result, future studies should review the outcomes and look further into the reasons why the cohort studied in this research suggest a different outcome to those of Hobfoll et al. (1989) and Lin et al. (2019).

Crossover and broaden- and- build

The crossover concept and the broaden-and-build model appeared to be both relevant and important to parents caring for neurodivergent children. My findings suggest that these two constructs can be extended to a new area of study and will benefit from further research and clarification. My findings need to be examined in greater depth to understand how crossover and broaden-and-build function in a cohort so much in need of the benefits and help these conceptual models can provide.

Proposed interventions

The interventions to strengthen resilience and coping mechanisms of parents coping for neurodivergent children proposed in this thesis have not been tested. They are derived from prior literature findings, and the outcomes of this research. They need to be trialled using an appropriate cohort of parents to assess their practicality and efficacy.

Conclusion

There has been a sustained growth in the number of children diagnosed with and awaiting assessment for neurodiversity. The negative effects and impacts that caring for these children can have on their parents, families, and wider society reinforce the relevance and importance of this study which sought to identify ways to help and support parents caring for neurodivergent children.

The objective of this study was to develop initiatives aimed at supporting mothers of neurodivergent children through the application of COR theory, alongside assessment and locomotion within the framework of regulatory mode. A review of the literature revealed an absence of studies within COR theory that integrate resource states with the regulatory mode orientations of assessment or locomotion. Similarly, research within regulatory mode that explicitly connects personal resources to an individual's resource situation is scant. This indicates a significant gap in existing literature. Furthermore, no studies were identified within the domains of COR or regulatory mode that explore the relationship between these two areas and the experiences of mothers caring for neurodivergent children. Although prior research has suggested the potential applicability of each theory to this demographic, there remains a clear gap in the literature regarding the combined use of these theories to support mothers of neurodivergent children.

This study employs an inductive methodology to generate evidence to address the gaps identified in the literature review. Initially, it identified associations between the two psychological frameworks of COR and the self-regulatory orientations within regulatory mode. With these associations in mind, this study explored how these two domains could be utilised to develop practical support strategies that may assist mothers in coping with, maintaining, and enhancing their resilience and well-being. These findings also advance the understanding of the COR resource passageway concept, which bolstered the potential feasibility of this study's proposal to develop initiatives aimed at improving the lives of mothers caring for neurodivergent children. The contributions of this study are delineated along with realistic and actionable recommendations. This chapter summarises the practical applications of this study and its outcomes, limitations, and opportunities for future research.

7 Professional learning as a researcher

Methodology and methods

My research approach was successful in providing a detailed understanding of the participants' characteristics, behaviours, thoughts, and emotions that were likely to have remained unclear using a positivist-based methodology. My qualitative research methods included semi-structured interviews for data collection, complemented by diary entries to support reflexive observations and personal reconciliation. I had not used qualitative methodologies previously and therefore felt I would be more at ease as the interviewer with an interview guide. I believe my own ease created a more comfortable and relaxed environment for participants. My focus was originally to find an approach that suited both myself and the participants, but I quickly realised that I needed to concentrate on the participants to enable the mothers to share their thoughts and feelings. Reference to, and use of my diary entries also supported my efforts to create ease and comfort for the parents. By recording and better understanding my own thoughts and feelings about what I experienced during the interviews, I was able to adjust my approach and focus to look at emerging issues in greater depth during subsequent interviews.

The use of semi-structured interviews and a reflexive diary proved to be an effective approach for the cohort of this study to explore the details of mothers' stories. This was particularly true for comments that were out of context, as the freedom of my interview approach allowed the mothers to fully express themselves and reveal additional and unexpected insights. For example, despite all the challenges and anxiety that their children brought, I was struck by the consistently positive way that mothers described their relationships with their neurodivergent children, and the level of love and devotion that they had for them. I was able to gain insight into and understand the mothers' need for self-respect and self-efficacy as well as the value they gained from companionship, belonging, and community.

My reflexive diary was particularly helpful in rationalising my thoughts during the journey, as I progressed through participant recruitment and interviews. I did not really have people to discuss my impressions, frustrations, and insights with each day, so writing my diary helped me record my positive and negative thoughts. As my diary was private, I was explicit about my thoughts and insights and could review and mentally deal with what I

had written, at the end of each day. The mothers I connected with, and investigated, presented me with a sample that had previously been outside my frame of reference, and they were not my intended participant sample.

Reflexivity helped me reconcile my prejudices and, more significantly, understand, empathise, and sympathise with the mothers. It also helped me maintain some space so that I could maintain a degree of dispassion, whilst gaining insight. Importantly, this process helped me better appreciate my reactions to what I was experiencing. The topic was new to me, and I needed to review and rationalise what I was experiencing. I tried to keep a distance and remain an observer, but as I understood the complex and challenging lives that the mothers led, the more my respect for them grew, and I found myself wanting to understand more about both neurodiversity, and the factors that marked out the mothers with greater resilience and coping capacities.

I see this greater immersion in my topic positively and as something that gives me a more rounded and balanced view of the world around me. The mothers' worlds became increasingly real to me and developed importance, and I ceased to see what I was doing as a merely an academic exercise. The opportunity to focus fully, for a long period, on a cohort of people who were previously not within my frame of reference is something I have drawn significant personal value from, both as a person and a researcher. It has helped me to more clearly identify myself and my place in my wider society, and reconcile how I relate to others, not an experience I had expected at my time of life. Learning, thank goodness, is lifelong.

My diary also contributed to the validity and reliability of this study through the additional analysis and depth that recording and reviewing my immediate thoughts provided. It offered me the opportunity to review and subsequently reconsider concurrent thoughts that I could not always rationalise at the time.

The participants required for this study suggested that recruitment was likely to be challenging. However, I did not anticipate the difficulties I experienced. I hoped that a significant number of mothers caring for a range of long-term sick children would be keen to offer their time to be interviewed, because they would consider my research as interesting as I did. Of course this was not the case. However, I was successful in

recruiting a cohort of mothers who were keen to tell me about their thoughts, experiences, frustrations, and joy. They were rarely people who simply wanted to be involved in a research project for the sake of research, although some were. Notwithstanding this, the significant value that providing the mothers with the opportunity to tell me about their thoughts and issues proved to be immensely valuable for collecting the rich data I needed for my analysis.

To answer the research questions, I purposefully looked for challenged parents facing extreme stressors and time restrictions who routinely made difficult decisions not faced by most parents. With hindsight, I did not understand the level of challenge or reality of recruiting such a sample. I looked at recruitment through a process-driven academic lens, rather than considering the practical challenges of mothers' day-to-day lives. I did not appreciate the relevance and impact of providing long-term care for sick children and the challenges it posed to the parents. Inevitably, it would not be easy to recruit volunteers. Prior research has frequently used gatekeepers, and I assumed that this would be appropriate and feasible for this study. I hoped that gatekeepers from institutions such as special schools, charities, local authorities, and hospital departments would identify appropriate potential participants; however, I found no gatekeepers. I also tried recruiting through posters on notice boards and word-of-mouth, but these proved to be ineffective contact routes.

With hindsight, my recruitment ideas were naïve in a world where other people lead busy lives dealing with their own stressors and challenging workloads. It demonstrated my limited knowledge of the subject I was studying and the remoteness of my understanding of the people I needed to support my study. I think, with the luxury of reflexion, that it is unreasonable to have high expectations of other people to recruit potential participants. It was neither fair nor realistic to expect people to have the same drive or commitment that I had, even when they were prima facie, committed day-to-day to the cohort I sought to recruit. Tempering my enthusiasm and expectations gradually but implicitly became my norm.

I realised that I needed to position myself in the contemporary and unique world of my proposed caregiver cohort to understand and identify possible routes to contact potential volunteers. I needed to understand how they were likely to feel comfortable communicating and what means of contact made them feel at ease. Realistically, it was difficult for me to understand this before I had undertaken my initial interviews, which reinforces the need for researcher flexibility. Ultimately, I sought-out modern outreach approaches likely to be used by my intended participants, and turned to social media, specifically, Facebook. I did not have a Facebook account, as I always shied away from sharing my personal life. Interestingly, this approach was predominant among the mothers in my sample who mainly used Facebook for information, knowledge, and news. Facebook proved to be effective; however, its use was time-consuming and required a detailed, structured, and coordinated approach to identify and follow through potential recruitment opportunities. Looking at my reflexive diary, I expressed frustration and annoyance that there was not an easy flow of potential participants keen to participate, which had been my hope. However, I recognised at the time that this just reflected my disappointment at not moving forward with participant recruitment as quickly as I had hoped, rather than any criticism of the potential sample.

The next step in tracking potential participants was also exacting, complex, and challenging, as I worked to bring potential wary recruits forward. Understanding that I was just one of several researchers trying to recruit study participants and that parents would reasonably be wary of putting themselves forward was an important learning point, as I began to grasp the concerns that recruits may have. I also learned that potential participants who appeared to have fallen by the wayside were happy to be chased and often valued it. These were busy mothers who needed to be reminded and helped during the recruitment process. I subsequently understood the extent to which these mothers were challenged, continually stressed, and needed to balance competing demands. I was just another pressure on them, and I had by necessity provided them with minimal details of the study in the flyers that I posted on Facebook. I was aware that the risk of becoming involved sat with the mothers, and it was my task to allay their concerns, help, and encourage them to follow through their initial interest.

I learned that participant selection and recruitment require careful and thoughtful preparation, should not be underestimated, and should not be rushed. Cohort recruitment should allow for unexpected outcomes and flexibility. In this study, the participants transpired not to be the planned mix of parents caring for long-term sick children I hoped

for but were all mothers who cared for neurodivergent children. The fact that I failed to reach my originally intended target audience of parents caring for long-term sick children was initially concerning. However, I quickly saw this positively as it clarified and focussed the nature of my study. Essentially, it provided me with an unexpected but welcomed focus.

I envisaged that the interviews would need to be addressed with care, and I spent time developing my interview guide and pre-and post-interview discussion points. I expected the participants would be busy and time pressed, and I wanted to ensure that the interviews were as efficient as possible while still providing a vehicle for the collection of rich and extensive data. A primary goal was to not waste the participant's time, and for them to feel that the time they committed had been used to a good effect. I was also keen for participants to see the interview positively and not become upset or insulted in any way. My diary shows a note that I felt I had no experience or insight into cohort I was recruiting and needed to be careful in all my approaches and dealings with them.

I also wanted the mothers to trust me and feel confident about sharing their stories. I needed them to have trust and confidence in me if they were to give me their time and willingly share their thoughts and experiences. My work on the pilot interviews proved to be effective and helped me achieve this and understand what was needed to refine my approach, techniques, and questions to achieve my research aim. From the initial pilot interview, it was clear that people's interpretations of simple questions or statements varied markedly.

I allowed flexibility in my planned (Braun and Clark, 2006) data collection and analysis processes. I was glad I did this, as it provided structure in a process with which I was a novice, which could have resulted in me losing focus and direction, which would not have served either me or the participants.

Ethically, I wanted to ensure that my process had rigor and developed valid and reliable findings through a controlled approach. I also wanted to ensure that busy mothers did not waste the time they committed to my recruitment and interview process, which may have been a consequence of less rigor. I believe that my method also reduced bias and generated findings from the data, rather than what I expected or wanted. Accepting that validity and

reliability cannot be guaranteed through a qualitative approach, I am keen to give readers of this thesis, and ultimately, my participants trust in my data. I took care to describe what I did to develop the data and produce my results and, where appropriate, used participants to help explain my approach and process and provide the reader with confidence and trust in the findings.

Assessed against the United Nations sustainability development goals (UN.SDG, 2024) and potential fast-track impacts (Reid, 2024), I believe the research outcomes are significant. With time and further work, this study could have an impact on the areas of understanding and awareness, preparedness, economics, health and well-being, decision-making and behavioural change, cultural, and other social impacts. Neurodiversity is a worldwide phenomenon, and it impacts parents and societies where the behavioural outcomes are accepted or condemned in varying degrees. The psychological and relationship impacts can be profound, leading to reduced parental efficacy, anxiety, stress, and exclusion, through societal misunderstanding and stigma. The need for parents to commit more time and care to their neurodivergent children can affect their careers, and impact industry through employee withdrawal, depleting the workforce of experienced staff.

The findings of this study therefore have the potential to affect mothers caring for neurodivergent children and their families as well as employers, charities, and other agencies linked to neurodiversity, including schools, local authorities, and healthcare bodies, which may extend to a range of other caregivers who face similar but nuanced challenges. To achieve impact, the initiatives proposed in this thesis will need to gain the attention of individuals and organisations who are in positions to influence the provision of help and support both outside and inside the work environment. Better working practices can lead to improved understanding and acceptance among employers and employees.

I hope that by contributing to this study, some of the mothers will have felt that their concerns and their lived experiences have contributed to potential solutions for not just themselves but also the wider communities they are part of. Several mothers wanted to raise their concerns. They had something to say about the way they perceived that they and their children were treated, and the inadequacies of provision for special needs. I hope

that I was able to provide an audience for them in some way and that at least some of them felt that their contributions mattered and may have been a catalyst for change. To be a catalyst for change, activities must flow from this research to create awareness and initiate actions. Approaches I am considering for publicising and taking forward the outcomes of this thesis include using social media, contributing to blogs, networking events, direct contact with charities, articles in academic and non-academic publications such as the Chartered Institute of Personal Development magazine, and presentations at academic and non-academic conferences.

Final reflections

Finalising the aim of this research was a journey that took time as it evolved from a significantly different concept. I began with an original proposal to compare empirical and qualitative data in conservation of resources theory and then added assessment and locomotion within regulatory mode to see how the two theoretical frameworks might work together. To generate valuable data, I decided to seek a cohort of parents who were significantly stressed and time challenged. This was planned to include parents caring for long-term sick children, but the recruited sample became mothers caring for neurodivergent children. This cohort of mothers was far outside my planned frame of reference and lived experience. They were a group of people about whom I had little understanding, and even less in common.

I spent time preparing how I would approach and work with the mothers to help me connect with them, so I could best understand their unique lives, hopefully with empathy and compassion. I conducted an extensive literature review and pre-reading to understand my expected cohort. However, because of my recruited sample, about whom I knew virtually nothing, I found myself investigating something that was in equal part unexpected, enlightening, and rewarding.

This study was enlightening because neurodiversity was not something I had really given any thought to previously. I was not aware that I knew any neurodivergent children or adults, and my knowledge of the conditions making up neurodiversity was extremely limited. The conditions were not recognised when I was growing up, and I really had no views on neurodiversity at the start of this study. The study was rewarding because I was studying and learning about something outside my experience and connecting with a

cohort of mothers whom I found genuinely interesting. For a short time and from a distance, I pried into the lives of the mothers to understand their thoughts, concerns, and challenges. I saw their commitment, pride, and satisfaction and the rewards they derived from their children. It left me routinely humbled and frequently in awe of how resilient people can be in the most challenging and stressful situations. From early on, I wanted to make a difference and believed that I could. It made me more driven and determined to complete this PhD quickly to realise its potential impact.

Once established, the focus of this study and the mothers who took the centre-stage in it, became the reason for the research journey and created purpose and focus for me. While I accept that a PhD provides a research apprenticeship, this study's subject matter transpired to give me a raison d'être beyond completing my research degree thesis. Indeed, the eventual purpose and justification for this study evolved during each supervision meeting and through my follow-up on the supervisor's comments, observations, and challenges. However, it was during my confirmation viva that the final evolution of this study solidified, and its purpose became clear for me.

Completing the work needed for this PhD has required dedication and an unwavering desire to develop a practical outcome for an ever-growing group of people who need help. Developing this research has changed me, both through the subject matter, and through an understanding of the need to maintain resolve, commitment, and day-to-day focus. I have not dipped in and out of the work but have committed to it each day and remained focused, with explicit plans and daily goals. I strived to develop a practical and meaningful solution for a generally misunderstood but dedicated and selfless cohort of mothers. I personally drew from the positivity and strengths I saw in each mother. Earlier this summer my daughter gave birth more than three months prematurely. As I write this section, my grandson reached full term and went home with oxygen. He is physically fine, but we cannot know how he will fare in coming years. If things do not progress well, I believe I will have greater compassion, understanding, and empathy than I had prior to embarking on this research project. This study has made me a better person.

Like all mothers caring for children, some of the mothers in my study coped remarkably well, some were demoralised, a few experienced severe psychological challenges, and some occasionally expressed suicidal thoughts. My feelings about those discussions could have

left me concerned, but the openness of my interview approach allowed the mothers to talk about their concerns. At the end of the interviews, the mothers commonly told me that they had found it helpful to talk about their lives and issues. They frequently said that the questions and easy approach I had taken had allowed them to think about their lives, with most saying that they had realised by the end of the interview that their lives were better than they had perceived them at the start of the interview. The interviews allowed them to talk about their lives, and despite all their challenges, they were better able to see positives that they had lost sight of. All of them gave me something of themselves, and I trust that I have demonstrated my desire and commitment to give something in return. I hope that this journey will continue and not end with this thesis.

This research topic has had a profound personal impact on me. It took me far outside my comfort zone and gave me the opportunity to conduct research in areas outside of my normal frame of reference. I now know that with prior consideration, thought, and preparation, I can, with an open mind, connect with and investigate with empathy and sympathy cohorts of people who are not within my lived experience. With hindsight, I am pleased that I took forward an investigation of a topic outside my comfort zone and explored a subject that was ultimately for someone else's benefit. I take pride that I can now identify with the mothers in my sample and relate to them. I have broadened my view of the world and where I see myself in it.

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APPENDIX A - PARTICIPANT INFORMATION SHEET



PARTICIPANT INFORMATION SHEET

Research Ethics Committee Reference Number: 22/LBR/008

Title of Study: Conservation of resources and regulatory mode: the passageways that bind us.

Thank you for your interest in taking part in this research study. Before you decide whether you will participate in the study, you need to understand why the research is being done and what it will involve. You do not have to take part if you do not want to. Please read this information, which will help you decide. Please take the time to read the following information carefully and discuss it with others if you wish.

1. What is the purpose of the study?

My study looks at how stressed and time-pressed people cope, and what helps them manage their lives to deal with the demands they experience. A key output of the study will be the identification of support for the well-being of working parents with significant child-caring responsibilities whose lives will be the focus of this study.

2. Why have I been invited to participate?

You have been invited because parents with a particularly challenging life balance due to enhanced caring responsibilities for school-aged children with significant restrictions for physical, mental, or medical reasons, who as a consequence, are likely to be particularly busy people who routinely need to make difficult daily choices. The criterion for participation is:

You will normally be a working parent (but this will be flexible), but certainly, the parent most involved or equally involved in caring for your child or children. Your child requires significantly greater care than may be expected from other parents.

The criterion is not prescriptive, but your child (or children) may have:

A physical, mental, or developmental restriction or health condition requiring care or treatment that can be expected to be from time to time or continuously significantly challenging, restrictive, or debilitating and can be expected to last over a year.

AND/OR

Your child has a continuous dependence on technology or other aids which has lasted for over six months and can be expected to last over a year.

AND/OR

Your child has malignancies that are progressive or metastatic and affect life function.

3. Do I have to take part?

No, you do not, and you can also ask questions about the research before deciding whether to take part. If you decide not to take part that is fine. If you are happy to volunteer to take part, you will be asked to sign a consent form, or more likely, you will acknowledge your consent through an email response. This will be sorted out in due course, but whichever option is used, you will have a copy of the consent for your records. Your consent will also be audio-recorded before your interview.

You can stop being part of the study at any time, or delay the process without giving a reason, but we will retain securely any information about you that I already have. You may withdraw from the study by contacting me before the interview, by telling me before or during the interview, or in the case of the questionnaires, by pressing the 'Exit' button or closing the browser.

4. What will happen to me if I participate?

Participation will entail an online interview lasting approximately 60 minutes on Microsoft Teams. I will arrange interviews with you at a time to suit you. The interview will be recorded and later transcribed by me for analysis. During the interview, I will ask questions to explore your experiences and thoughts about aspects of your busy life. The interviews will focus on you.

All interview recordings and transcripts will be stored securely and will remain confidential. All research materials will be shared with my supervisors at the Liverpool John Moores University. Nothing will identify you, your child, or your family in the final research session. Your responses will not be linked to your name or any personal details in any publication and any information will be used in such a way that you cannot be identified. If any quotes from you are used you will not be named and you will not be identifiable. For more information on this please see paragraph 8 below.

The interviews are essential for your participation in the study, but you should be content with the entire process. You are free to decline to be interviewed at any time. You should be comfortable stopping the interview recording at any time whilst continuing to participate in the study. You are also free to end your participation at any time and therefore withdraw your participation.

5. Are there potential risks in participating?

It is not anticipated that you will have any cause for concern during the interview; however, if at any point in the interview, you become uncomfortable, we will stop the interview immediately. Talking about life challenges may be upsetting and if this is the case you may wish to consider utilising the services of a confidential debriefing service, such as Oxfordshire Mind's information line to speak to a well-being worker on 01865 247788 (Monday to Thursday, 9:30 am to 4:30 pm). Alternatively, if you do not feel like talking on the phone, you can text Oxfordshire Mind with your questions about mental health and well-being using 07451 277973 (Monday to Thursday, 9 am to 4 pm).

6. What are the benefits of this study?

The hoped-for benefits of the study for wider society are to provide new avenues for research in two established theories, whilst also identifying general means to support the psychological well-being of parents caring for children with chronic health conditions.

7. Payments, reimbursements of expenses, or any other benefit or incentive for taking part.

This study received no external funding or sponsorships. There will be no payment or any benefit or incentive for taking part in this study. Unfortunately, I cannot reimburse any expenses you may incur.

8. What will happen to the information/data provided?

The information you provide will contribute to the overall study data. Any study data from which you can be identified (e.g., from identifiers such as your name, date of birth, audio recording, etc.), is known as personal data. Your participation in this study will not involve the collection/use of personal data, other than to allow appropriate contact to be made and maintained, and for background study information.

All personal data will be kept safe and secure. Only I will be able to see your name or contact details. The personal data collected will include:

- Contact details.
- A record of consent (which will include your name).
- Study data. I will use a code/identifier for you so that you cannot be directly identified from the data. Interview recordings will be deleted once the interview transcript has been verified as accurate and an evaluation has determined that it has no further research value.

Study data/records of consent/contact details will be kept for three years after the study has finished when they will be destroyed.

Your participation in this research will be audio recorded in Microsoft Teams and your data will be processed by the Microsoft Teams built-in facility. It is planned to use a backup voice recording through the iPhone voice recording app. I will carry out subsequent reviews and corrections of the transcript from the recording. These arrangements will be confirmed with you before the interviews. Use of these online facilities may mean that your data is transferred by Microsoft, or Otter ai to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. However, appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third-party platform as soon as possible and stored securely on my password-protected computer and encrypted iCloud account.

It is not intended to use a human transcription service to type up the recorded interviews. However, if it is subsequently decided to use a transcription service, this will be discussed with you.

I will not attempt to capture your IP address or any other information that is not voluntarily provided. Although every reasonable effort will be taken, confidentiality during actual Internet communication procedures cannot be guaranteed.

I will keep confidential anything I learn or observe related to an illegal activity unless it is related to the abuse of children or vulnerable adults, money laundering, or acts of terrorism. In certain exceptional circumstances, where you or others may be at a significant risk of

harm, I may need to report this to an appropriate authority. This would usually be discussed with you first. Examples of these exceptional circumstances in which confidential information must be disclosed are as follows:

- o I believe you are at serious risk of harm, either from yourself or others.
- o I suspect that a child may be at a risk of harm.

9. Who do I contact if I have a concern about the study or wish to complain?

If you are concerned about any aspect of this study, please contact *Alex Barnes* (A.Barnes@2022.ljmu.ac.uk) and Dr Maddy Stevens (m.stevens@ljmu.ac.uk). We will do our best to answer your query. You should expect a reply within ten working days. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at Liverpool John Moores University who will seek to resolve the matter as soon as possible:

Chair, Liverpool John Moores University Research Ethics Committee; Email: <u>FullReviewUREC@ljmu.ac.uk</u>; Tel: 0151 231 2121; Research Innovation Services, Liverpool John Moores University, Exchange Station, Liverpool L2 2QP

Please note that you may only participate in this survey if you are 18 years old or older.

Note: a copy of the participant information sheet should be retained by you.

APPENDIX B - PARTICIPANT EMAIL CONSENT



EMAIL CONSENT - informed consent from research participants via email.

Study title: Conservation of resources and regulatory mode: the passageways that bind us.

Research Ethics Committee Reference Number: 22/LBR/008

Please read the following statements.

If you are happy with all of the statements, please copy and paste the table and your name/date into an email and send it to me at a.barnes@2022.ljmu.ac.uk, stating that you consent to the statements, which will be considered to constitute your consent to support me with the study.

If you have any questions about the study or the statements below, please do not hesitate to contact me through the email below.

Principal Investigator: Alex Barnes, LJMU postgraduate research student

LJMU Email address: A.Barnes@2022.ljmu.ac.uk

LJMU School/Faculty: Business and Law

LJMU Central telephone number: 0151 231 2121

1.	I confirm that I have read the information sheet dated 29/03/2023 (version V4) for the above
	study, or it has been read to me. I have had the opportunity to consider the information, ask
	questions, and have had these answered satisfactorily.
2.	I understand what taking part in the study involves.
3.	I voluntarily consent to be a participant in this study and understand that I can refuse to
	answer questions I can withdraw from the study at any time, without giving a reason and
	without penalty or my legal rights being affected.
4.	I have been advised about any potential risks associated with taking part in this study and
	have considered these before consenting to participate.
5.	To the best of my knowledge, I meet the inclusion criteria outlined in the information sheet
	for this research. If this changes later during study participation, I agree to notify the
	researchers immediately.
6.	I give explicit consent for this study to process my data as described.
7.	I understand that the investigator will be unable to guarantee control of access to authorised
	viewing of the audio recordings/video recordings taken during the study and I am happy to
	proceed.

I understand that the study involves taking audio/video recordings of me and I am happy to proceed. I understand that I will not be able to participate in the study if I later decide not to be recorded. I understand who will have access to the personal data provided, how the data will be stored, and what will happen to the data at the end of the project. 10. I understand that my information may be subject to review by academic supervisors from Liverpool John Moores University for monitoring and audit purposes. I agree for my contact details to be stored to contact me and I understand that agreeing to be contacted does not oblige me to participate in any further studies. I understand that personal data may be transferred to countries outside of the European Economic Area where there may not be the same level of protection of peoples' privacy as that demanded by law in the UK (for example storage in an encrypted cloud account) 13. I understand that personal data will be retained beyond the duration of the study. I understand that personal data will remain confidential and that all efforts will be made to ensure I cannot be identified in reports or any further outputs. I understand that parts of our conversation may be used verbatim in future publications or presentations and that all efforts will be made to ensure I cannot be identified in reports or any further outputs. 16. I understand that even though all efforts will be made to ensure I cannot be identified, there remains a possibility that I may be indirectly identifiable in the disseminated study findings. I therefore acknowledge the potential risks of being identifiable in reports and any future outputs when the findings of the study are disseminated. 17. I understand that if reportable information is revealed, the investigator will be obliged to break confidentiality, as explained in detail in the information sheet. 18. I am 18 years of age or over. I agree to take part in this study.

Name of Participant

Date

Data Protection. Any personal information we collect and use to conduct this study will be processed in accordance with data protection law as explained in the Participant Information Sheet and the <u>Privacy Notice for Research Participants</u>.

APPENDIX C - SUMMARY OF THE CHILDREN'S DEMOGRAPHICS USED IN THE FINDINGS

Participant	Main carer & decider	Care needs	Children's condition	Child age & care condition period
Arden	Mother	Two children. Significant support for son but manages 7 days a week care team/care plan as son needs 24/7 care. Mother is carer for daughter.	Son has CP, paraplegia, and other conditions (generalised communication, learning difficulties, incontinence, autism) in full-time education (3 days a week). Daughter has autism & ASD, learning difficulties, sensory and communication problems - in full-time education.	Son aged 20 affected since birth. Daughter aged 16, diagnosed age 8.
Bellamy	Mother	Four children. Eldest son is fully dependent on mother or another carer for most things. Full carer support 3 other children without care needs	Eldest son has CP and uses a wheelchair. Stairlift at home. Profound moderate learning disabilities, doubly incontinent, hips fully dislocated. Fully dependent on parent or another carer for care, including toileting.	Son aged 17 affected since birth but was adopted as young child.
Briar	Mother	Two children. Both children home educated. A couple of lessons three days a week through the local secondary school via online education. No carer support.	Daughter autistic and chronic fatigue syndrome. Son waiting to be assessed by CAMHS for autism and ADHD.	Daughter aged 13. Son aged 8.
Brighton	Mother	Three children. Both boys behavioural and emotional issues. Needs constant care. Daughter neurotypical. No carer support.	Eldest son ASD (autism spectrum disorder) considered Asperger's level, no learning difficulties, but social and behavioural difficulties. Middle son diagnosed ADHD and sensory difficulties – is medicated.	Son aged 11. Date of diagnosis not recorded. Son aged 9. Date of diagnosis not recorded. Daughter aged 7.
Callaway	Mother	Two children. Daughter attends specialist school. Needs complete care. Son in a mainstream school.	Daughter autistic. History extreme dangerous behaviours and escaping.	Daughter aged 17, diagnosed aged 2. Son aged 15, diagnosed after sister.

			Son autistic. Relationship	
		Has carer support.	issues. Violent to mother and sister.	
Clover	Mother	Two children. Both boys at primary school. Need extensive care from mother. No carer support.	Eldest diagnosed ADHD, generalised anxiety disorder and autistic traits. Youngest diagnosed ADHD and autism.	Son aged 7. Date of diagnosis not recorded. Son aged 10. Date of diagnosis not recorded.
Cypress	Mother	Two children. Eldest is academic, intelligent, and mostly friendly when he wants to be, but has few friends and self-esteem issues. Medicated this year, so calm now. Can have defiant behaviours. Younger brother is neurotypical. No carer support.	Eldest diagnosed ADHD, with ADHD and ODD (oppositional defiant disorder).	Boy aged 9. Diagnosed October 2022 Boy aged 7.
Eversen	Mother	Two children. Eldest at home with mother as not able to attend school - has a couple of hours home education provision each week. Younger brother neurotypical. No carer support.	Eldest diagnosed autism, ADHD, depression, and other comorbidities. Son can need help quickly. Constant checks.	Boy aged 15. Date of diagnosis not recorded. Boy aged 13.
Halston	Mother	Two children. Both attend state school. Both children need daily support for their condition. Younger brother Neurotypical. No carer support.	Elder son has ASD and social-behavioural challenges.	Boy aged 8 years just diagnosed (2023). Boy aged 5 (Neurotypical).
Honor	Mother	Two children. Older one needs a lot of activities to keep him busy. The younger one doesn't like competitiveness and gets quite stressed. No carer support.	Eldest ADHD, anger management & Anxiety, dyslexic. Youngest ADHD & Autism, dyslexic.	Boy aged 11. Diagnosed 2020. Boy aged 9. Diagnosed 2022.
Hollis	Mother	One child. Limited carer support.	Son has ADHD and autism (Aspergers), dyslexic. Medication for concentration and to settle him.	Son aged 9. Diagnosed 2020.

			Issues with transitions,	
			separations, and change.	
Jupiter	Mother	Five children. All have struggled with the school environment. Masking all day - exploding and screaming all the way home. Youngest son recently started specialist school. Girls recently moved to small school and coping better. No carer support, but much help from husband.	All children diagnosed autistic and have very different profiles needing different care approaches.	Boy aged 16. Boy aged 14. Girl aged 10. Girl aged 8. Girl aged 4. Date of diagnoses not recorded.
Kingsley	Mother	Two children. Autism issues, difficulty at school and unwinds at home. Youngest son neurotypical. No carer support.	Oldest son diagnosed autistic. Medicated.	Son aged 11. Diagnosed 2020. Son aged 9.
Kit	Mother	Two children. Son complex needs, now home full time with currently no education support. Has limited funded PA support.	Son diagnosed autism. Dysregulation and communication problems. Unable to cope in school. Developmental delays, speech & language difficulties, sensory difficulties. Daughter suspected ADHD, ASD, dyslexia, and dyscalculia. Waiting to go on waiting list for assessment. On the high functioning end of the spectrum.	Son aged 8. Diagnosed 2021. Daughter aged 9.
Landry	Mother	Three children. Boy is high functioning attending specialist school. Daughter struggled in mainstream primary school. Went to a private special school. No carer support.	Son diagnosed autism, PTSD. Marfan's (recent spinal surgery). Daughter diagnosed autism. Suspected ADHD. Dyslexic DCD (dyspraxia), and hypermobile diagnosed at about 7 or 8 years. Both children mental health difficulties. Daughter self-harmed and both tried to take their own life.	Son aged 20. Diagnosed 2017. Daughter aged 18. Diagnosed 2022.
Lexington	Mother	One child. Special school.	Son diagnosed ASD (atypical autism) and global	Boy aged 12. Diagnosed 2017.

		Limited carer support.	developmental delays, possible PTSD.	
Luxor	Mother	Two children. Apart from neurodiverse care, the main responsibility is monitoring medication and administering it. No carer support. Shares care with husband.	Both children diagnosed autistic. Son also diagnosed with obsessive-compulsive disorder.	Daughter aged 12. Diagnosed 2022. Son aged 10. Diagnosed 2022.
Merritt	Mother	Three children. Main issue for mother is youngest daughter must sleep with her every night. Eldest daughter is settling down now and beginning to cope. Son at University. Not yet diagnosed with a neurodiversity. No carer support.	Eldest daughter ADHD (attention deficit / hyperactivity, GAD (generalised anxiety disorder), endometriosis, ME (prolonged tiredness), autistic tendencies. Youngest daughter autistic PDA (pathological demand avoidance), PCOS (polycystic ovary syndrome), CFS (chronic fatigue syndrome). Son awaiting assessment for ADHD or AuDHD. (autistic & ADHD), hypermobile, and transitioning female to male.	Daughter aged 21. Diagnosed 2007. Daughter aged 14. Date of diagnoses not recorded. Son aged 23. Not yet diagnosed.
Ocean	Mother	Son attends local mainstream college. Son needs the care a child would normally need. No carer support.	Autism diagnosis. Brain damage. Epilepsy due to chromosome 18Q deletion established at age 17. IGA neuropathy or Berger's disease - an autoimmune condition affecting kidney function. Delayed puberty.	Son aged 19. Brain damage from seizures aged 2. Autism diagnosed 2022.

APPENDIX D – PARENT DEMOGRAPHICS USED IN FINDINGS

Participant	Carers work	Age of participant	Husband or partner support	Stated financial concerns
Arden	Self-employed Part-time	45	Yes	No
Bellamy	Freelance consultant	45	Yes	No
Briar	Freelance consultant	48	Yes	No
Brighton	None	32	No	Some
Callaway	Employed part- time	56	No	No
Clover	Employed full-time	43	Yes	No
Cypress	Employed part- time	36	Yes	No
Eversen	Freelance consultant	46	No	No
Halston	Self-employed Part-time	37	Yes	No
Honor	Employed full-time	41	Yes	No
Hollis	Employed part- time	46	Yes	Some
Jupiter	Zero-hours sessional work	42	Yes	No
Kingsley	Employed part- time	43	Yes	No
Kit	Self-employed part-time	45	Yes	No
Landry	Self-employed part-time	53	Yes	No
Lexington	Employed part- time	57	No	Some
Luxor	Employed part- time	41	Yes	No
Merritt	Employed part- time	55	Yes	No
Ocean	Employed part-time	46	Yes	Some

APPENDIX E - COPY OF FLYER USED TO RECRUIT PARTICIPANTS

Would you be willing to take part in an online interview to contribute to a Doctoral research study?



The purpose of the study is to look at how severely time-pressed and stressed people cope, and what helps them manage their lives to deal with the demands they experience.

A key output of the study will be the identification of support for the well-being of working parents who have particularly significant and complicated child-caring responsibilities.

You will need to be a working parent over 18 years old who has a particularly challenging life balance due to caring responsibilities for school-aged children with a significant long-term condition or illness - full participation criteria will be provided to potential participants.in an information sheet.

Interviews will be on Microsoft Teams and will be arranged at a time that is convenient for you. The interview is likely to take about an hour or so.

Unfortunately, there is no remuneration for taking part, but your contribution would be valuable.

If you are interested in participating, please email Alex Barnes using the email or QR code:

a.barnes@2022.ljmu.ac.uk



APPENDIX F - PILOT 1 INTERVIEW EXTRACTS

Pilot 1 interview extracts						
Extract A						
Participant	Amanda (Nurse aged 51)					
Original question	Participant comment	Revised question				
How would you describe your strengths?	That's sounding more like an interview question. I know you're doing an interview, but maybe reconsider it'?	What would you say are the key positives in your life now? (Follow-up - what's contributed to that in your life?)				
What would you say to people are your weaknesses?	'And that's where they probably break down in tears. You may need to think about that question'.	What would you say are the main negative aspects of your life now? (Follow-up - what's contributed to that in your life?)				
Extract B						
Participant	Hannah (Trader aged 30)					
Original question	Participant comment	Revised question				
What are your thoughts for the future? How do you look at the future?	What? Uh, I don't know what that's going to going to look like. I think, suppose the treatment their daughter is having now is not going well. A parent will probably be in tears by now, or not able to carry on, but if they've got a chronically ill child, then maybe they're in a better situation. So, I think it's, I think it may be difficult'.	This question was revised to provide 2 separate questions: What are your thoughts about the future? And What gives you hope?				

APPENDIX G - THE FINAL INTERVIEW GUIDE

INTERVIEW PROTOCOL/GUIDE

Preamble.

- a. Hi #XXX#
- b. How is today going?
- c. Are you OK to go ahead with the interview as planned?
- d. We'll start the interview in a few minutes, but if you are OK, I'd like to start an audio recording of the interview now, while we are just chatting so I can check the recording works. I also have a backup audio-recording system.
- e. Any questions on the consent form or the information sheet?
- f. Whereabouts do you live #XXX#?
- g. Just to reassure you, apart from when we are talking in the interviews, I won't use your name anywhere else I'll anonymise you.

I may quote what you say in my write-up, but no quote will be linked to you by name.

Whatever you say is considered confidential.

- h. Please try to relax all your answers are correct—I need what you think and feel. Just be honest and try to be as open as you can say whatever you want.
- i. If you need me to ask a question again just say.
- j. If you need a break during the interview for any reason, just tell me even if it's just because you want to make a cup of tea, or an Amazon delivery arrives, or you need a break from me.
- k. If you don't want to carry on at any point, just tell me and we will stop.
- 1. Hope about an hour or just over
- m. The interview is about you, not your children I think there is one question about your children.
- n. The main questions are about how you cope and manage, about aspects of your personality, and how you use your time.
- o. I think that's all I want to tell you, but is there anything you want to ask me at this point?

Are you OK to start the interview now?

Let's just go through a few BACKGROUND QUESTIONS.

- 1. Male/Female (not to be asked)
- 2. Could you tell me if you're currently in a relationship? (If yes: how long in the relationship? If no: how long on your own?)
- 3. Could you tell me the education level you and your husband/wife or partner reached?
- 4. Could you tell me if your spouse or partner is in employment? FT/PT?
- 5. Do you own your own home, or do you rent?

- 6. Would you be willing to tell me your age?
- 7. How do you take your child to medical appointments and hospital visits?
- 8. Do you consider you have a sufficient family income to live "adequately"?
- 9. Who's at home at the moment? (boys/girls?) Do you sometimes have help at home?
- 10. And I believe you have a son with XX, is that correct is he/she in Ed? a little info.

STRESSORS

- 1. Can you describe a regular day in your life (is this different at weekends)? (Establish when child became ill).
 - a) The extent of the care that #NAME# / your child needs from non-healthcare professionals? i.e. that you or your husband/partner provides.
 - b) Normal caring duties required from you each day? (See if different at WE).
 - c) Who makes non-professional care decisions day-to-day? (What sort of decisions need to be made?)
 - d) Who would you say is the primary carer?
 - e) How would you describe the general effects on you of your caring responsibilities?
- 2. Your job? Could you describe your normal working day in your job (if they have one?)
- 3. At the moment, would you say, you?
 - a) What would you say is your approach to life? Is it generally positive or negative, or would you describe in some other way? (Probe why, what)
 - b) Feel generally upbeat or down at the moment? (Probe why, what)
 - c) How sensitive and supportive are you to other people? Would you say you can be sympathetic to others (Probe why, what, examples)
 - d) Would you say you are generally weary, tired, or drained at the start of the day (which) or do you have plenty (or enough energy)? (Probe why, what) clarify we can all feel tired when we wake up so outside this concept.
- e) How do you deal with complex issues? Can focus effectively concentrate? (Probe why, what sort of things)
- 4. What would you say are the greatest demands and challenges on you? (What do you particularly struggle with?)
- 5. What helps you most with all your demands and challenges? (Probe physical & psychological).
- 6. Do you find these demands and challenges stressful or some other descriptors? (How frequently do you get stressed?)
- 7. If you get stressed, what helps you deal with stress? (e.g., deal with yourself or seek help from others if so who?)

SUPPORT - people, organisations, groups, society

8. Who do you consider to be your close family? (How much do they support you?)

- 9. You told me about your close family, what would you say are your wider support networks? (People/ groups/organisations/society). Length of time?
- a) How often do you engage with your support networks? (e.g., family, wider networks)

COMMUNITY?

- b) What help do your support networks provide?
- c) What would you say you gain or benefit the most from each of your networks?
- d) What support would be most valuable for you if different from what you get now?
- 10. Overall, how important are your support networks for you? (e.g., which, who are most important)

RESOURCE CARAVANS & RESOURCE CARAVAN PASSAGEWAYS

Section 3 (of 4 total)

- 11. Looking back over your life, what would you say were the key events for you, starting with your childhood? (positive and negative, respectively).
- 12. And looking back again at your life since childhood, who have been the individuals who have had major impacts on you and your life, and why? (positive and negative, respectively).
- 13. Are the memories you have generally positive or negative? (What things were particularly positive and/or negative)
- 14. And looking at those key events and the people we just talked about, is there anything you would change or do differently? (why/why not).
- 15. What would you say are the key positives in your life now? (What's contributed to that in your life history?)
- 16. What would you say are the main negative aspects of your life now? (What's contributed to that in your life history?)
- 17. What do you think the future holds for you? (Why do you say that?)
- 18. Do you think your past life has influenced your future outlook?
- 19. What gives you hope? (i.e., hope for the future)

VALUING TIME

- 20. In general, which would give you greater happiness, more time, or more money? (Has your valuation of time changed over the years if so, why?)
 - a) If your work offered you the choice between a £250 voucher or a day off work, which would you choose? (Explain your thoughts on this)? What if there is a routine weekly offer?
 - b) Are options available for you to have more time or more money? e.g., part-time work.
- 21. If you ever have spare time, what do you do say, if half a day became free? (Why do that / for what benefit?)
- 22. If you had more money but no more time than you had now, what would you do with that money? (Why and for what benefit?)

LAST SECTION

TIME MANAGEMENT BEHAVIOURS

- 23. What do you do to relax? (on your own/with your child or children/with your close & wider family)
- 24. You have a lot to cope with in your life. How do you best use the time you have available?
 - a) To what extent do you feel you can take control of your time and manage it? How do you feel that you have done that? (Mental accounts of time use, plan daily life, set & order goals, prioritise, lists and scheduling).
- 25. If there was a wider family get-together, who would normally organise that (why is that?).
- 26. Think about setting yourself a goal, or having something to achieve which is most important to you, perfection and accuracy, or speed and achievement? why is that do you think?
- 27. When you set yourself a goal, what would you say makes you achieve it successfully?
 - a) Would you describe yourself as a 'high energy' or a 'low energy' person? Why do you say that?
 - b) Would you say you are generally a 'go-getter', or would you say you are content to let life take its course?
 - c) Are you happier being the one to get on and do the things that need doing, or are you happiest when others get on and do them?
 - (d) Are you the sort of person who tends to take on lots of tasks at the same time, or do you focus on one thing at a time? Why do you take this approach?
 - (e) When you set yourself goals, are they generally long-term, immediate, or short-term?
- 28. When you put time into doing something and it doesn't happen well or doesn't happen at all, what are your thoughts / how do you react? (Example you make plans to meet with friends, but you find that they are unable to attend at the last minute or they will be late arriving).
- 29. Are you the sort of person who puts off doing something until you must do it, or someone who gets things sorted out as soon as possible? (Why is that?)
- 30. Would you describe yourself as someone who evaluates yourself and others a lot? (Evaluating and comparing people as individuals and how they do things compared to yourself)
- 31. Last question. Do you think you have a good life balance? Why? What gets you through a poor life balance?

How do you envisage your life would look if you had a good life balance? /How well do you achieve satisfactory balance?

Post interview

I think we are all but done now - you may be pleased to hear.

That was all excellent, very helpful, and inciteful for me.

How are you feeling?

How did you find the experience?

I think that the recording has worked well.

Is there anything at all you want to add #NAME#?

OKAY - if I need to come back to you at all - don't expect that I will, but are you Ok for me to contact you? By email?

I appreciate I have used a lot of your time, but is there anything you want me to explain about anything?

Any friends who may be interested in taking part?

Fine, let's sign off now, but thank you again for your time and honesty.

APPENDIX H – PILOT 2 INTERVIEW EXTRACTS

Pilot 2 interview extracts						
Extract A						
Participant	Claire, 40 (Counsellor)					
Original question	Participant comment	Revised question				
Can you tell me about your childhood and youth?	What do you mean by that, are you asking me about where I lived, my school? I'm not sure what you're getting at and don't know how to answer the question, sorry'.	The question was revised to incorporate several questions looking at the participants caravans and passageways. Revised question 1: Looking back over your life, what would you say were the key events for you – starting with your childhood? (Positive and negative).				
		Revised question 2: And looking back again at your life since childhood, who have been the individuals who have had major impacts on you and your life, and why? (Positive and negative).				
		Revised question 3: Are the memories you have generally positive or negative? (What things were particularly positive and/or negative)				
		Revised question 4: And looking at those key events and people we just talked about, is there anything you would change or do differently? (Why/why not).				
Extract B						

Participant	Rebecca, 45 (Marketing Exe	ecutive)
Original question	Participant comment	Revised question
How do you relax?	Well, do you mean with a sick child or without a sick child, and what you mean when you ask when I'm at home or when I'm not at home? I'm not sure about that question being clear'.	Revised questions: You have a lot to cope with in your life. How do you make the best use of the time you have available to you?" And What do you like to do when you relax?
Extract C		
Participant	Claire, 40 (Counsellor)	
Original question	Participant comment	Revised question
How much do you feel in control?	What are you trying to get at by this question? Are we talking about the child or some other aspect of their life?'	The purpose of this question was to gather information on aspects of assessment and locomotion. Locomotors believe they have a level of control over time because they use organisational methods such as lists, diaries, and similar methodologies. The question was adjusted to: To what extent do you feel you can take control of your time and manage it? How do you feel you do that? (Prompt mental accounts of time use, planning daily life, setting & ordering goals, prioritising, lists, scheduling).
Extract D		
Participant	Claire, 40 (Counsellor)	
Original question	Participant comment	Revised question
With all the competing things going on in your	Well, I think that. I think that may be leading me a little. I like the day-to-day life part of the	Following discussion, the question was changed to:

life day-to-day,	question but is that one you need	Do you think you have a good
what in your view	to discuss?'	life balance" (Prompt "Why do
is a satisfactory		you say that, how well do you
balanced life?		achieve satisfactory life balance"?)
		, ,

General

Another question looking at the participant's thoughts on the future was: "what are your thoughts for the future"? This question had previously been amended during pilot 1 but was also questioned by Claire. After consideration the question was developed into 3 separate questions:

Amended question 1:

What do you think the future holds for you? (Why do you say that?) Amended question 2:

Do you think your past life has influenced your outlook on the future?

APPENDIX I – Stress and hope and assessment and locomotion evidence

Stress and hope						
	Positive or negative approach to life					
Summary assessment	Positive stress					
Evid e n ce	It's really hard. I'm probably more negative if I'm honest than I am positive. Some days, I feel I just can't cope at all, and I just don't feel there is enough time. If I can give myself time, I feel guilty. I'm not sure what it is, but I used to be a good sleeper and I think that when I go to bed, that's when my brain starts thinking, and I start to think, you know, maybe if I had just sent that e-mail or maybe if I chase them again, you know, it's always about the kids. It's always about the kids future, constantly fighting, constantly having to do things to help them, yeah, that's keeps me awake at night. It doesn't end. I must do that independently from my family because of the weekend situation, otherwise I feel guilty because then I feel like my husband doesn't get enough respite. It's kind of the guilt all the time that stops me from doing a lot of things. Me and my husband don't really go out on our own. The other day, when I was in therapy, I mentioned that I just wanted to drive into a tree. It's not that I want to kill myself, it's just I just want a break, because if I was in hospital, I wouldn't have to do all this every day.					

Assessment and Locomotion					
	Approach to goal achievement				
Summary assessment	Mixed assessment and lo comotion				
Evidence	If I'm gonna do something, I want to do it well. I want to do a good job, because I don't see the point in doing things messily. You might as well not bother. I'm probably a bit of a perfectionist. I just try and think what is the end objective what am I trying to achieve here? What do I need to get to that point? Who do I need to connect with? What resources do I need? Where can I get support? I just try and look at it in an organic allencompassing kind of away.				

APPENDIX J - REGULATORY MODE ASSESSMENT AND LOCOMOTION EXAMPLES OF CHARACTERISTICS AND EMPHASES

Name	Description	Files	References
ASSESSMENT		5	22
Accuracy, not speed focus	Focus more on accuracy than speed during decision making and task engagement	4	6
Pace should be slower	Slower pace for higher than lower assessors and locomotors.	1	2
Loss of specific goal focus	With lost sense of control of own time.	1	1
Poor task progress & completion	High assessors may disrupt smooth task flow by stopping more often to evaluate their selection of means or their choice of goals when engaging in a particular activity.	1	2
Rumination & decision & decisiveness paralysis	Decision and decisiveness paralysis, rumination - lost in thought. Assessment should be inversely related to decisiveness because it inherently involves a more extensive consideration of which goal should be pursued at a given time, or which means to a particular goal may best be selected.	4	7
Extrinsic, external motivation link	Activities are the means to an end, nonautonomous motivation.	3	5
High standards desire	Focus on how not when goals & rewards are accomplished.	3	7

Name	Description	Files	References
LOCOMOTION ORIENTATION			
Action orientated	Action may be a preferred strategy by high locomotors for themselves, but not necessarily among others.	8	20
Able to move forward	Locomotors may find it relatively easy to let go of prior goals and standards.	1	1
Act quickly	For goal achievement.	2	2
Delay intolerance	Locomotors' intolerance of delay.	1	1
Aversion to delay	Locomotors' impulsivity, aversion to delay and tendency to choose goals with high attainment expectancy cause them to rush things in pursuing their goals.	1	1
Commitment to change	High locomotors should evaluate change in general more positively and commit to it.	1	2
Decisive	Locomotion-oriented individuals are more likely to leap without looking and engage in decisive and even impulsive action.	4	5
Conflict resolution	More willingness to resolve interpersonal conflicts.	3	4
Faster pace & less accurate		3	4

APPENDIX K – Excell data of Resource caravan, regulatory mode, resource passageways and time

Participant	Stress Assessment	Hope Assessment	Resource Caravan Assessment	Assessment and Locomotion Orientation	Passageway summary	Time value summary	Time management summary
LUXOR	Positive stress	LIMITED HOPE	Inadequate resource caravan	MIXED	Challenged resource passageway	TIME	ASSESSOR
KIT	Positive stress	NEGATIVE HOPE	Inadequate resource caravan	MIXED	Challenged resource passageway	TIME	MIXED
HOLLIS	Positive stress	LIMITED HOPE	Inadequate resource caravan	MIXED	Challenged resource passageway	TIME	MIXED
BRIGHTON	Some stress	LIMITED HOPE	Limited resource caravan	MIXED	Challenged resource passageway	TIME	MIXED
KINGSLEY	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
JUPITER	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
HONOR	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
HALSTON	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
EVERSEN	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
CYPRESS	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR

ARDEN	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
LANDRY	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	AN NTERMEDIATE RESOURCE PASSAGEWAY	MONEY	LOCOMOTOR
Bellamy	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
OCEAN	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
CLOVER	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Positive resource passageway	TIME	LOCOMOTOR
BRIAR	Negative stress	POSITIVE HOPE	Adequate resource caravan	LOCOMOTOR DOMINANCE	Challenged resource passageway	TIME	LOCOMOTOR
LEXINGTON	Some stress	LIMITED HOPE	Limited resource caravan	LOCOMOTOR DOMINANCE	AN INTERMEDIATE PASSAGEWAY	TIME	LOCOMOTOR
MERRITT	Positive stress	NEGATIVE HOPE	Inadequate resource caravan	ASSESSOR DOMINANCE	Challenged resource passageway	TIME	ASSESSOR
CALLAWAY	Some stress	LIMITED HOPE	Limited resource caravan	ASSESSOR DOMINANCE	AN NTERMEDIATE RESOURCE PASSAGEWAY	TIME	ASSESSOR

APPENDIX L – EVIDENCE DEMONSTRATING NEGATIVE, SOME STRESS, AND POSITIVE STRESS

Evidence of negative stress

It's 24/7 and then, it's the mental load. It's just always there, and because I'm aware I make more of an effort to make sure I get time to myself. I much better able to cope with it if I've had a bit of exercise first thing in the morning, it sort of sets me up right for the day and all that, right? I can cope with the world then'. (Clover).

I seem to have been quite successful managing us to where we need to be. It all just takes so much longer, and I put the success down to my academic ability to look at the problem analytically. You know, this is what I need to do to solve the problem, and then having the writing skills to be able to put that down in writing and communicate effectively'. (Clover)

I feel more positive about Monarch now as well, and also, he's got a diagnosis now and he's on medication. We can do things now, go places without worrying about his behaviour and yeah. We've been through a difficult time, I guess, but yeah, I'm definitely much happier now'. (Cypress).

The new meds are having a positive effect on the family because if everyone is calmer, it's all calmer, I'm calmer, my husband is, and his brother is, you know?

Once he started medicating, the teachers were like, oh my goodness, where is this child come from?'

Honour)

Evidence of some stress

'But generally, you know, I am quite positive, (laughing) depends on the person. Yeah, really it does. Umm, yeah, I don't have much left after children and really, at work I have to be a certain person, and that then means that I don't have too much left after that. But I try'. (Clover).

'I was phoning the GP, but he couldn't help because we needed to go to CAHMS. CAMHS have a four-year waiting list, but the school are saying Monarch's behaviour is bad, and we just stuck in this cycle. I mean, how do you help this child is crying after school because he's been embarrassed by his teacher, and feels is not understood and then feels he's also not understood at home either because there's, you know, his mum and dad are then shouting at him because he isn't doing his homework or whatever'. (Cypress)

When there's been a buildup of difficult situations and decisions and tightens, that can develop into a sort of mental and physical stress, and maybe a little desperation because it's maybe being in a situation and that you have so little control over, yet you absolutely can't and wouldn't walk away from it. So, you know, it's very much out of your hands in that you have no choice but to sort of just muddle through it, and that can feel quite desperate. Nothing happens if I don't make the calls or kind of seek the help that he needs'. (Eversen)

Evidence of positive stress

(It's) 'definitely stressful.

Stressful and tiring.

The lack of time, there isn't enough time to do everything that I need to do in the day'.

(Bellamy)

I just feel weary and stressed out, and sometimes not even able to picture what is happening and having to reread things again.

Maybe my concentration isn't there enough? Yeah. Sometimes I even struggle with films, you know to keep my concentration, to keep track of what's happening'.

(Callaway)

'Stressful, yes, but I guess it makes me feel guilty because I know that I'm basically handing over to my husband, but he needs a break to, and he also wants to hang out with me, but I'm just not up to it'. Kit)

How else do I deal with all the emotional stressful things? Well, I drink far too much alcohol, way too much, but I'm trying to get a handle on that, but it is a kind of reward for me at the end of the day'. (Lexington)

'Yes, [the caring responsibilities are] very stressful, to the point where it's become so stressful that I sometimes don't know what to do about it, or how to deal with it, but you have to carry on anyway, there's'.

It's tricky because I've had poor mental health in the past and I am on antidepressants, and I have also been seeing a therapist for about five years'. (Luxor)

APPENDIX M - EVIDENCE SUGGESTING POSITIVE, INTERMEDIATE, AND NEGATIVE HOPE

Evidence demonstrating positive hope	Evidence demonstrating intermediate hope	Evidence demonstrating negative hope
"Clearly, you hope it's going to sort itself; things do. You know that parenting mantra; this too, shall pass. Things change, so there's no point in stressing out in the moment". (Briar)	"But they can have normal relations and they can be happy, whatever that looks like, I guess. They don't need to be married, just so long as they are happy". (Luxor)	"I don't know how that will sort out, or that when he's 18, will he go to college and have a life of his own, because I just don't know". (Lexington)
I will carry on being a mummy and working. Yeah, I'm just quite happy with my lot and watching them go through school and juggling everything". (Cypress) " to just give myself that reminder every year, things change; improve massively. But when you're in it, you can't see it. So, I try and remind myself of that now, but that is maybe why I don't look too much into the future. It's hard to imagine how things will be different, they do look different, because people grow up and change". (Eversen) "Yeah, we're just holding on for like 10 years when they can just maybe [be] left at home or	"I make breakfast, but he can do some things for himself now like find the cereal, put milk on it, and eat it I must remind him to sit down. He knows to take his medication in the morning". (Hollis) "I struggle with the future, and I worry all the time about that Truman at 11; we've got an understanding when 90% of time he can communicate his needs to me, and I can communicate my needs to him, and we can meet somewhere in the middle. I just hope we can get there too with Sullivan". (Brighton) " It was stressful with all of it, but because now he's [older son] a bit more capable of regulating himself, so	"I think something else that really gets to me, and of course every parent worries about their children, but if you sit around parents with regular children and listening, you overhear conversations of the regular children and their problems, I just think oh my God, I wish I could say this was a problem for me. My child will never ever do this thing, but if he did, I would be so grateful". (Kit) "I have no idea what that means for my children. I worry about all the hate in the world. My children will manage their own challenges, but the anxiety that Polly's got and with the limitations that Susie has" (Merritt)
something. Well, maybe a bit longer than that, but it's just seems so far away sometimes. We can do it". (Halsten)	the world is opening up gradually". (Clover)	

APPENDIX N – REVIEW OF BRIGHTON, LEXINGTON, MERRITT, CALLAWAY FOR RESOURCE CARAVAN & ASSESSMENT AND LOCOMOTION

Participant	Stress Assessment	Hope Assessment	Resource Caravan Assessment	Assessment and Locomotion Orientation	Age	Education level	Life balance	Working	Parmer	Soc life	Therapy / Meds	Neurodiver- gent	Onldren's complexity
LUXOR	+ve stress	Limited	Inadequate caravan	Inermediate Pass ageway	41	7	No	Yes	Yes		Yes		Sig
KIT	+ve stress	-ve hape	Inadequate caravan	Poorpassageway	45	6	No	Yes	Yes	Limited		Yes (Self- diagnos ed)	Sig
HOLLE	+ve stress	Limited	Inadequate caravan	Poorpassageway	46	6	Yes	Yes*	No*	Limited	Yes	Yes	Less Sig
BRIGHTON	Some stress	Limited	limited carayn	Poorpassageway	32	5	Yes	No	No*			Yes (Self- diagnos ed)	Sig
LEXINGTON	Same stress	Limited	limited caravan	Inermediate Passageway	57	6	No	Yes	No	Limited			Sig
MERRITT	+ve stress	-ve hope	inadequate caravan	Poor passageway	55	7	Yes	Yes	Yes	Poor	Depressed		Sig
CALLAWAY	Some stress	Limited	limited caravan	Inermediate Passageway	55	6	Yes	Yes	No				Sig

APPENDIX O – KEY RESOURCE SITUATION OF EACH PARTICIPANT

	Cognitive	Financial	Positive mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support
Arden	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Cypress	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Halston	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Honor	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Jupiter	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Kingsley	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
	Cognitive	Financial	Positive mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support
Bellamy	Adequate	Adequate	Intermediate	Adequate	Adequate	Adequate	Adequate	Intermediate	Adequate
Clover	Adequate	Intermediate	Adequate	Adequate	Adequate	Adequate	Adequate	Intermediate	Adequate
Eversen	Adequate	Intermediate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Intermediate
Landry	Adequate	Adequate	Adequate	Adequate	Intermediate	Intermediate	Adequate	Adequate	Adequate
Briar	Adequate	Adequate	Intermediate	Adequate	Adequate	Intermediate	Adequate	Intermediate	Adequate
Ocean	Adequate	Intermediate	Adequate	Adequate	Adequate	Intermediate	Adequate	Intermediate	Adequate
Brighton	Adequate	Intermediate	Intermediate	Adequate	Adequate	Intermediate	Intermediate	Intermediate	Intermediate
Brighton	Adequate	Intermediate	Intermediate	Adequate	Adequate	Intermediate	Intermediate	Intermediate	Intermediate
Brighton	Adequate Cognitive	Intermediate Financial	Intermediate Positive mindfulness	Adequate Health	Adequate Social	Intermediate Psychological	Intermediate Personal Skill	Intermediate Time	Intermediate Immediate family support
Brighton					•				
Brighton Callaway					•				
J	Cognitive	Financial	Positive mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support
J	Cognitive	Financial	Positive mindfulness	Health	Social	Psychological	Personal Skill	Time	Immediate family support
J	Cognitive Intermediate	Financial Inadequate	Positive mindfulness Inadequate	Health Adequate	Social Adequate	Psychological Intermediate	Personal Skill Intermediate	Time Adequate	Immediate family support Inadequate
J	Cognitive Intermediate	Financial Inadequate	Positive mindfulness Inadequate	Health Adequate	Social Adequate	Psychological Intermediate	Personal Skill Intermediate	Time Adequate	Immediate family support Inadequate Immediate family support
Callaway	Cognitive Intermediate Cognitive	Financial Inadequate Financial	Positive mindfulness Inadequate Positive mindfulness	Health Adequate Health	Social Adequate Social	Psychological Intermediate Psychological	Personal Skill Intermediate Personal Skill	Time Adequate Time	Immediate family support Inadequate Immediate family support Adequate
Callaway Luxor	Cognitive Intermediate Cognitive Adequate	Financial Inadequate Financial Adequate	Positive mindfulness Inadequate Positive mindfulness Inadequate	Health Adequate Health Adequate	Social Adequate Social Intermediate	Psychological Intermediate Psychological Inadequate	Personal Skill Intermediate Personal Skill Inadequate	Time Adequate Time	Immediate family support Inadequate Immediate family support Adequate Adequate
Callaway Luxor Merritt	Cognitive Intermediate Cognitive Adequate Adequate	Financial Inadequate Financial Adequate Adequate	Positive mindfulness Inadequate Positive mindfulness Inadequate Inadequate	Health Adequate Health Adequate Adequate	Social Adequate Social Intermediate Inadequate	Psychological Intermediate Psychological Inadequate Inadequate	Personal Skill Intermediate Personal Skill Inadequate Inadequate	Time Adequate Time Inadequate Inadequate	Immediate family support Inadequate Immediate family support Adequate Adequate Adequate
Callaway Luxor Mernitt	Cognitive Intermediate Cognitive Adequate Adequate	Financial Inadequate Financial Adequate Adequate	Positive mindfulness Inadequate Positive mindfulness Inadequate Inadequate	Health Adequate Health Adequate Adequate	Social Adequate Social Intermediate Inadequate	Psychological Intermediate Psychological Inadequate Inadequate	Personal Skill Intermediate Personal Skill Inadequate Inadequate	Time Adequate Time Inadequate Inadequate	Immediate family support Inadequate Immediate family support Adequate Adequate Adequate
Callaway Luxor Mernitt	Cognitive Intermediate Cognitive Adequate Adequate Adequate	Financial Financial Adequate Adequate Intermediate	Positive mindfulness Inadequate Positive mindfulness Inadequate Inadequate Inadequate	Health Adequate Health Adequate Adequate Adequate	Social Adequate Social Intermediate Inadequate Intermediate	Psychological Psychological Inadequate Inadequate Inadequate	Personal Skill Intermediate Personal Skill Inadequate Inadequate Intermediate	Time Adequate Time Inadequate Inadequate Inadequate	Immediate family support Inadequate Immediate family support Adequate Adequate Adequate Adequate Adequate
Callaway Luxor Merritt	Cognitive Intermediate Cognitive Adequate Adequate Adequate	Financial Financial Adequate Adequate Intermediate	Positive mindfulness Inadequate Positive mindfulness Inadequate Inadequate Inadequate	Health Adequate Health Adequate Adequate Adequate	Social Adequate Social Intermediate Inadequate Intermediate	Psychological Psychological Inadequate Inadequate Inadequate	Personal Skill Intermediate Personal Skill Inadequate Inadequate Intermediate	Time Adequate Time Inadequate Inadequate Inadequate	Immediate family support Inadequate Immediate family support Adequate Adequate Adequate Adequate Adequate

APPENDIX P - CARAVAN 1. ADEQUATE, EFFECTIVE RESOURCE CARAVAN (PARTICIPANT EXAMPLE; HALSTON)

Colour legend

Adequate resources
Intermediate resources
Inadequate resources

HALSTON	Resource Caravan 1 Adequate, effective Resource Caravan (All resources are adequate)
Cognitive	"I'm more the paper [work], he [husband] looks after the car, and I do the paperwork. So, you know, I'll do our tax returns as well, so paperwork is on me".
Financial	"No, I I've got a job, which means if the kids want something, like the younger one's birthday's coming up, he would like a Switch computer, and we would never have been able to even think about being able to get him one of those. But now, it means we can do that now Yes, I would say we do [have enough family income] overall".
Mindfulness	"I mean, I try and have a positive mental outlook anyway. If you do negative thoughts, they make you go down, so I do try and keep upbeat. I just live on a day-to-day basis with all of this. I'm not great at overly planning. I'm very appreciative of what I have, so, I'm not lonely, because I can turn around and whinge to a mate".
Health	"If I was on my own, I'd probably actually try and do some exercise. Because of my new hours, I'm not getting time to do any exercise, so I might go a long walk.
Social	"I've got a network of a couple of other mums whose children are also neurologically diverse, and we just catch up and either drink wine or go for a meal and although each of our children are different, even though they've got similar or the same diagnosis, their children are different from my children. And so, it's communicating with other people and just having a crutch to lean on, and you know, that really helps".
Psychological	"So, I'm actually very happy and life is good at the moment, um, yeah, I would say everything's just rosy, and I can't complain anything. I always say to my boys, come on, let's find something positive about this. He's [son] like there's nothing to be positive about, and I'm like, yes, there is, the sun is shining or whatever".
Personal skills	"So, we can say, you know, you need to say to her, are you alright, do you need anything, do you need chocolate, you know? Does she want to come round here like".
Time	"I don't like my job. Although it sounds amazing, I have too much work, not enough hours in the day, and it means I'm spending less time with the family and I'm not really liking that because it's not what I signed up for. But yeah, I'm alright at the moment".
Immediate family support	"We do try to share the responsibilities, my husband can get flexible time at work, and does come to meetings if both of being involved will be useful".

APPENDIX Q - CARAVAN 2. ADEQUATE TO INTERMEDIATE RESOURCE CARAVAN (PARTICIPANT EXAMPLE; BRIAR).

Colour legend	Adequate resources
	Intermediate resources
	Inadequate resources

	Resource Caravan 2
BRIAR	Adequate to intermediate resource caravan
	(Resources are either adequate or Intermediate)
	(· · · · · · · · · · · · · · · · · · ·
Cognitive	"Yeah, so I've got a few roles [working from] at home, and I've also got this regional role
	and I've got the local [health service committee] role, as I'm also currently working on
	contract with XXX as a director, which is the organization for [committee] chairs".
Financial	'Being comfortable financially is a big positive too".
Mindfulness	"Taking control and actively saying I don't want any of this to look like that past, so I'm
	gonna use it to make better and different choices for me and my own family".
	"I've done a lot of work and therapy to be able to utilise these things in a positive way. I mean,
	that's how I ended up doing what I do now, because I didn't want anyone else to go through
	what I had gone through".
	"There's no point saying I wish we were somewhere else because we aren't".
Health	"If I had a magic wand, I'd have known I was autistic from when I was young, because
	knowing that has been completely transformative for me, and realising that this is what I am,
	not, that it's all wrong, that you're not broken, and that's why you don't fit in".
Social	"When I've got time, I meet friends and go for walks".
Psychological	"Well, I try to be positive, but there's, you know, all the potential negatives".
	'I try and be positive, but I don't always feel very positive, but hey, we are where we are, and
	it is what it is. It's like, what can we do with what we've got"?
	"But I think I spent most of most of my life trying to fit in and feeling like I was kind of in a
	in a boat without a paddle going down the rapids, but now I feel much more like I'm in a
	different hoat and I've got control over where it goes and what it does".
Personal	"I don't want my childhood and my experience to be my children's experience. And so, it's
skills	very much about learning from it and breaking some of those generational things.
Time	"Stress demands, you know, the amount of stuff that that needs to be done and making choices
	around that".
	"I have to have a lot of time where I'm doing absolutely nothing. I need the time to regenerate,
	so it's not non-stop full on". "The thing is, because of the way that I've designed my life, I am able, you know, apart from
	weeks like this, when it's a bit crazy, to take time and, that's something I'm making sure of
	going forward".
Immediate	"[Talking about caring for the children] So really, it's just us, me and my husband. Yes. I
family	mean, in working hours it's mainly me, but you know, really, if we were looking at the overall thing
support	and especially if we're thinking about Poppy and her illness and all the hospital stuff, I deal with all
TT	of that".
	I ~

APPENDIX R - CARAVAN 3. MIXED RESOURCE CARAVAN WITH WEAKER FINANCIAL, MINDFULNESS, AND IMMEDIATE FAMILY SUPPORT (PARTICIPANT; BRIAR).

Colour legend Adequate resources

Intermediate resources

Inadequate resources

	Resource Caravan 3
CALLAWAY	Mixed resource caravan with weaker financial, mindfulness, and
0 111	immediate family support
Cognitive	"Sometimes I get into trouble with that [focussing on complex tasks], especially if letters
	come. You know, I'll try to ignore them sometimes when I shouldn't, or just put things off
	because making decisions is difficult sometimes too. It might not even be anything particularly
771	tricky, it's just another thing to consider".
Financial	"A lot of my decisions are about, just scrimping and saving, not even saving, but just getting
	through, you know, getting by. So, more money would sort a lot of things. Our house is kind of collapsing around us and more money would take away those worries. I'd just feel more
	settled, less anxious if I had more money, I wouldn't really think about staying up by my son's
	school twice a week. I would just come back, but you know, because of the price of fuel, I stay
	up there".
Mindfulness	'The last few weeks or month, things have just closed in, and I 've had a lot going on. Things
	have got difficult, partly because things with my son, to the extent we are actually having a lot
	of support from social services and that has impacted on me emotionally a lot So, I think
	the past month I've got very frustrated with this situation, and you know, it's taken its toll.
	So, I'd say that's led to a little dip lately".
Health	"But also, the voluntary work in the park, I like that. There's a group of people there and
	we, you know, we get on really well. We enjoy being outdoors and we cleared the stream, litter
	pick and cut back like the plants and things. That's really good as well. I enjoy that. Yeah,
Social	I like being outdoors". "We'll [participants mother] see each other regularly through the week, maybe five out of
300121	seven days. And she gives me emotional support too, yea, most things, yeah, we'll talk about
	things too"."[participant has an] Extensive support network, friends, face to face and online,
	weekly, and church, I would go to church at least three out of four weekends in a month".
Psychological	"I just feel weary and stressed out, and sometimes not even able to picture what's happening
	and having to reread things again. Maybe my concentration isn't there enough? Yeah.
	Sometimes I even struggle with films, you know, to keep my concentration, to keep track of
	what's happening". "But generally, you know I am quite positive".
Personal	"And sometimes if I really need to do something, you know, I need to ring up about something
skills	or fill out a form, when I get round to it or I don't get it completed or I need somebody's help.
Time	Well, that just frustrates me that I've got to that point, and I can't complete it".
Tille	"On certain days, certain things are done. I'm allocating tasks to days or parts of days to make sure things get done. I'll book work for three days of the week or it will go on to the
	next. There's lots of times when I've said, oh, no, I can't do that, or I haven't got the time".
Immediate	"[negatives in current life] Definitely around my son and where he's going, and how is he
family	gonna manage in the world, yes, where where's that going. He attacked me in February, and
support	after that, he's just stopped talking, so that's a real big thing. So that's a real challenge for us.
	All these meetings are because of his behaviour and for child protection, because his sister's
	witnessed these things. She was at home when it happened as well".

APPENDIX S - CARAVAN 4. MIXED RESOURCE CARAVAN WITH STRONGER COGNITIVE, FINANCIAL, PHYSICAL, AND IMMEDIATE FAMILY SUPPORT (PARTICIPANT EXAMPLE; MERRITT)

Colour legend Adequate resources

Intermediate resources

Inadequate resources

	Resource Caravan 4
MERRITT	Mixed resource caravan with stronger cognitive, financial, health, and immediate
	family support
Cognitive	"There are certain routines I have when I'm functioning well, and I have to have routines
	in place. I use reminders on my phone and my iPad and so on".
	'I'm a great planner. Usually, I've got lists everywhere. I've got plans everywhere. I've got
	calendars everywhere. Unfortunately, I've usually mislaid them by the time the event comes
	around".
Financial	"We are in a fortunate position that we're both have a fairly decent wage, and the mortgage is
	quite low now".
Mindfulness	"But now I'm not very functional really. I am so overwhelmed that I do just nothing really
	because the brain fog comes down and it becomes a period of inactivity, but I'm not relaxed.
	It's not a recuperation, it's just nothingness".
	"It [sewing] takes mindfulness, and you have to pay attention and be completely absorbed in
	what you're doing. And I can't remember the last time I was able to do anything with total
TT 11	mindfulness".
Health	"I just bury it. I can't let it take hold too much. I've actually let it take hold in work, which
	is why I'm off work. I just couldn't keep all the balls in the air, so the work balls got dropped.
Social	It's not really dealing with my stress; it's just putting it on hold".
Social	"[The] Local community doesn't exist [for her or her family]. And also, Polly's anxiety won't allow her[daughter] to socialise really".
	"I have started seeing this counsellor who lives quite locally. I'm four weeks into that, I've got
	another six weeks left, but seeing a professional is not quite the same as having a friend.
	Everybody's drifted away".
Psychological	"[I'm] Outwardly upbeat. Inwardly I struggle, and I'm quite like dying.
, 0	Yeah, I think I'm approaching a level of burnout. Approaching is probably wrong, I probably
	am in a bit of a burnout now.
	I'm so stressed and it's such a chronic situation. I feel depressed every day because actually I've
	run out of feelings. I'm a blank. I don't have anger. I can't take the time out because I'm
	autonomous on automatic screening. You're not a person anymore".
Personal	" I've got the school support. I have support from CAMHS, well, Suzie's got support
skills	from CAMHS and yet it's destroying me and to an extent her as well. The family dynamic
	is certainly not a normal one. We are just about coping; it might be by fingernails and skin of
Time	teeth sometimes". "We are considering me cutting my hours because I'm actually off sick at the moment and part
Time	of the reason for that is the level of support I have to provide for our youngest".
Immediate	'I'm struggling as it is, and I've got my husband's support.
family	I don't know what we'll do when the kids leave. I don't know how that's going to work. I'm
support	kind of hoping we'll [she and her husband] just gravitate more to each other because we don't
11	get the opportunity very often at moment".
	"It's only when I stop and have this kind of conversation that I realise that my husband and
	I haven't had a night out for a very, very long time, in fact we don't go out. I think we've had
	probably had 4 evenings out in the last eight years as a couple".

APPENDIX T - CARAVAN 5. PREDOMINANTLY INADEQUATE MIXED RESOURCE CARAVAN (PARTICIPANT EXAMPLE; HOLLIS)

Colour legend	Adequate resources
	Intermediate resources
	Inadequate resources

Cognitive "I'm always doing things, doing so much and juggling so many things, it's just that my brain craves activity. I find it difficult to relax". " often, it's just easier to lie in front of the TV, to be quite honest". "I'm managing, I'm on top of things mostly I think". Financial "Well, we're very frugal, and if I bny things, they either come from ALDI or they're second-band clothes for myself. I don't go to the bairdressers, and I do without things that I don't need". Mindfulness "I'do struggle a bit with the unspoken aspects of friendships, the expectations, but I just think it's kind of obvious, you know what I meant, but I didn't say it. And then it's like, resentment as well". "I'met two momen there [at an event for mothers of ND children]. But again, I've been feeling a bit disappointed with the lack of outreach from their side". "Right now, I feel like I'm entering menopause and I've had blood tests to confirm it. I'm on HRT to help with like mood issues because they can be worse certain times each month. I like outdoor swimming pools or water generally, with a magazine or a book, having a little swim, chilling out". "Last night she [her mother] put him [her son] to bed because I went out for water gymnastiss". "I guess that other than my weight, which gets me really frustrated, you know I used to go out and dance a lot, and I would just drink and dance and never put on any weight. I would like to have more like opportunity for exercise or you know less opportunity for sitting around eating chocolate on my own". Social "Knowing I have been autistic my whole life and I've lost jobs and I've lost friendships; I've lost relationships. I've struggled with certain issues which now makes sense looking back on it I'm a social person, but if I feel things are one-sided, I get down about it Unfortunately, because of my way of communicating sometimes people think I'm rude, so I've been removed from certain groups that I've found supportive. I find that hurtful. It'd be nice to have s	HOLLIS	Resource Caravan 5
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	1 sychological	The stressjan. Often on the weekend, $1 m$ so exhausted 1 just let my son which anything on TV . I don't really care. But he needs 1 on 1 attention and support and he's very demanding,
whereas other kids his age would be a little bit more independent. There was one day he just		
took himself off to grandmas and I just lay in bed like a zombie and honestly, didn't even care.		
That was a low point when I just felt should be able to be a better mum and a better, more		
capable parent".		
	Personal skill	"Yeah, I think looking at things we can change, and changing those, obviously you feel
frustrated and depressed if things don't go how you want, or you don't feel in control of how		

	things are going. I feel that's a constant struggle because I'm always struggling with
	understanding why certain things go the way they do".
Time	"I've never enough time, so [she would like] more time.
	I would like to be in a relationship. Unfortunately, I don't have a lot of time to date.
	I'm trying to write another book, and I wish I could take more time for my writing and creative
	development".
Immediate	"It's me at home with my son.
family	I guess things with my mum could be better. She's very judgmental about certain things and
support	she can be very pig-headed I sometimes think she just thinks I'm making it all up.
	It's the same with my siblings, and I wish I had a closer relationship with them I just
	feel actively excluded and not considered, yeah".
	" my brother, but he doesn't have contact, he doesn't make any effort and again, that's
	another source of frustration for me and there's been instances where I felt very frustrated and
	angry with him, and that's another relationship I've withdrawn from".
	"I currently have a plan to buy the house my mum lives in, so my son and I would be in the
	same building with my mum. It would be easier, and we could have a less stressful routine for
	both of us".

APPENDIX U – PARTICIPANT QUOTES RELATING TO RESOURCE PASSAGEWAYS

Empowering Passageways						
Childhood	Adult life	Current life				
"I had a very good childhood, a very privileged childhood really, went on lots of holidays and lots of good experiences. I went into private education in xxx. Weight has always been a bit of a thing throughout my life, and I had a year six teacher who offered to go on a diet with me to lose weight". (Halston) "I definitely remember looking up to both my parents as sort of role models as I was growing up and then perhaps not so much family, but friends and maybe some teachers and being kind of inspired by some, and what I saw in them". (Eversen)	'T've learned more from my children than I think I did in the 30 odd years before I had them. Yeah, they've changed my life in a positive way, yeah, definitely. The key positive is my children; they definitely keep me going". (Clover) 'When I'm at work, I'm with my friends, they're nice people to talk to. I get a buzz from my job which is looking after people and feel really appreciated and important, and I feel my role's important, so that's a bit of a high for me". (Cypress)	"[Things in her life that are positives now] I'd say my husband obviously, and my mum and dad. They live an hour away from us and they have 24 grandchildren, because I'm one of five children and we all have huge families, we are very close. We talk every day and message every day". My husband's family are also close family, his mum and his twin brother and his sister. (Jupiter) "And my family are also positives. We have a kind of community where we are and a supportive group of friends? We have a little kind of community allotment also and when I do go down there, I enjoy it". (Bellamy)				
Opening Passageways						
Childhood	Adult life	Current life				
"Being an undiagnosed autistic in the 80s at school, had a massive impact, lots of bullying. When I was seventeen, one of my closest friends was murdered, and my parents did nothing to support me, absolutely nothing, which baffles me. When I was six months old, my mum went into hospital with post Natal depression and none of my family looked after me. I was put into care. I've been raped. That was obviously a huge thing. I had a fair amount of emotional abuse from my dad and my brother throughout my childhood. He [brother] was always the Golden Boy it was always very difficult because I couldn't talk to (my mum) about". (Briar)	"I was made redundant a couple of times as well - I found it life changing in a positive way". (Briar) "I got a job when I was nineteen, and I started work at basically the bottom of a utility company. But I asked them to sponsor me for a degree, which they did, and that's how I got my MBA. I ended up as one of the senior managers. But it was hard work, it was a very misogynistic organization, but I think the challenge was part of making me who I am now. But I think the 80s and 90s were very different to the workplace now. I was the only female manager at that level and was the only one that actually came within budget and thought out outside the box and was prepared to challenge what others said". (Landry)	"I think if I changed anything, I wouldn't be who I am now, and I think that makes me push really hard to be a good parent. I know that might sound a bit strange, that maybe I push myself too much, I don't. I think I'm never complacent about it, and I try not to be complacent about it, but I just feel I need to give my children not material things, but more, saying I love you and to show them affection. The more subtle things, because I didn't have that growing up". (Luxor)				

Limiting Passageways Childhood Adult life "The things I remember about my childhood that stick out are sad things like, you know, like my granddad dying, and being in hospital for ages before he died. And moving schools. I went to a Convent school, a 30-mile trip on a train and a bus to a dodgy

part of Manchester, with broken glass on the top of the walls. I found that very difficult, very strict and run by nuns, many in their 70s and 80s. A very strange experience, and years behind as a school". (Lexington)

"The worst thing that happened ever in my entire life was my dad died when I was 28. Some would say I've never recovered from that. And then, getting married because I was 40, but that's not the best reason to get married, and it turned out to be a complete and utter disaster. I had IVF treatment, massively traumatic and didn't work, I got pregnant twice and had two miscarriages. I'm not thinking many happy things, am I?" (Lexington)

'I've decided that my daughter will live with me. I wouldn't want her to go into any supported living or anything like that. I've no idea with my son, I think he'll go to college next September for two years, I don't know where that will be. I don't see him going to the workplace or apprenticeships or anything like that. So yeah, just in education. And then for myself, I'm not sure. I guess I'll continue working or be able to keep working. I don't know if that will mean reducing my hours, you know, just because as my daughter finishes school, she might have less hours out of the house actually as she gets older, so I'm not sure how that

will work out". (Callaway)

Current life

Restricting Passageways		
Childhood	Adult life	Current life
"Parents divorced at age 2 Grew up with grandparents born in 1906 and 1918, a Victorian upbringing, very controlled, very stifled. I lived there until I was about 27. Relationship with brother was and still is a slightly unusual dynamic. Could call him Machiavellian. "He [Dad] was quite a controlling man a sad man really. I got his approval only twice. [She was] a loner at school, and I was picked on massively [she] did not have a fun time at school, I hated school. I just sat at the back and did the minimum I could get away with. I didn't do well in some where I probably should have done". (Merritt)	'When my son was little, I had a sort of crisis and had social services involvement. I was struggling with aspects of being a single parent, sleeping issues and no balance with work and trying to get enough rest at home. I had accessed counselling through my GP, which is limited generally to 12 sessions which is a joke because you can't get anywhere in six or 12 sessions and my GP referred me to CBT and also with a peer group. Knowing I have been autistic my whole life I've lost jobs and I've lost friendships; I've lost relationships. I've struggled with certain issues which now makes sense looking back on it, for example, my boss in the UK sent me on anger management training". (Hollis)	"There are times when I look and I think I'm lost, and I'm not a person anymore, but I've kind of accepted that and that's just the way it is. I have recently started seeing a counsellor to try and improve things for myself". (Merritt) "At the moment I've kind of given up my hopes and dreams because there's just nothing for them right now". (Kit)

APPENDIX W – DATA STRUCTURE

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
It's fighting the systems. If they didn't make it all so hard, things would have been a lot easier. (Briar) I just haven't found them at all helpful or having the ideas or even knowing what's available out there. So that's been frustrating and so we're kind of locked in this situation where I'm not really getting anywhere as far as my son's concerned, you know, with getting the help that's needed. (Callaway) He only has another year where he is, and so we need to start looking at other options and there's a kind of dreaded transition to adult services which we don't really hear many positive things about. (Bellamy) If I say I don't want to participate, they say they'll just withdraw all services. So that is not helpful really, yeah. (Arden) And kind of like school places and stuff like that, trying to get support, anything to do with the Council, you're literally, unless you phone every single day, you just you just don't get anywhere. (Brighton) I do feel like the system did let down my older two. We knew that there were issues with Rolly, and we took him to almost every clinic going and were told at each point that there was an issue, but not enough to do anything about, and you don't want them on Ritalin do you. So, everything was looked at in isolation and that was really frustrating. (Merritt)	Local authority support [is] unhelpful and stressful	Negative effects from institutional support	External factors
No one gives you a this is a how to guide for how to deal with neurodiverse children. You know, both the children are so different. (Honor) It's all so over overwhelming and it's hard to know like what you're supposed to be doing. There's no guidance on what I can do, what should I do, so understanding about similar situations and accessing the right information. (Kit) Having someone to lead me through what to do would have been really helpful. There was no sign posting of where to go, where to get help. (Cypress) Having someone to talk to, somebody who actually understands and can potentially offer strategies and support, not necessarily to solve the problem. Because I think a lot of	Limited practical support stressful		

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
people with children, with SEN, it's not an overnight magic wand. It's like fixing the			
Rubrik's Cube, you know, you fix one bit and then the other bit breaks. (Brighton)			
My biggest battle is the education system which is just not fit for purpose. (Clover)	School support		
So, we were stuck in this loop of Monarch getting expelled from school and being called in	poor and stressful		
to go and get him. Then the head teacher threatening he'll be expelled again. You know,			
not really knowing what to do with him. (Cypress)			
But once he started medicating, the teachers were like oh my goodness, where's this child			
come from. It was like they thought the child was new to the school, but you know, they			
just weren't engaging enough with them to get through to them. (Honor)			
He left that school after one year because they just had no compassion and didn't care			
about him, just because he didn't fit their expectations. (Ocean)			
We initially tried to get into school on a reduced timetable but there came a point when I			
asked myself why was trying to get him in at all when fundamentally the school was not			
meeting his needs. It was not doing him any good. Anyway, he is better off at home and			
better out of the school environment. (Kit)			
So, often people are not trained to understand disabilities and they will tell you they can't	Mainstream school	Children's	External
accommodate you because you're asking for something extra. (Hollis)	attendance	schooling	factors
I think the old school very much took the approach of this is the education system, and you			
need to fit into it, and if you don't fit into it, then you're either causing trouble, or you don't			
belong here. (Jupiter)			
My daughter started secondary school in September, she attends a standard comprehensive			
school, and was self-harming at school, only at school. So hopefully now we've got a			
diagnosis it will be easier for her. (Luxor)			
He was in a special school for high school. He was at a small mainstream junior school,			
and it was obvious that he was never going to cope in a large mainstream environment.			
That was the best decision we ever made. He was very happy at his high school, he made			
friends, was settled and he managed to gain a few qualifications, (Ocean)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
We now have a SENCO in our secondary school who totally gets everything and is 100%			
supportive. When Suzie needs time, it's given, and when she needs extra support, it's given.			
In her mocks, she's got extra time, and she's got brakes which don't add on to that extra			
time. She's got a room to herself to do her exams in. She's got one to one support to sit			
the exams. We are so lucky. (Merritt)			
Since the diagnosis, their attitudes have definitely changed. Yea, before, they were just			
seeing him as rude and naughty, but they seem a bit more sensitive to him now, so they'll			
give him space and not pressurise him to do what they want so much, so I think they let			
him come round a bit slower. (Cypress)			
Hugh [son] is at home now though, because we've just taken out of school to home educate	Child being home		
him because he's waiting to be assessed by CAMHS for being autistic and ADHD. School	educated		
just wasn't working for him at all. (Briar)			
We initially tried to get into school on a reduced timetable but there came a point when I			
asked myself why was trying to get him in at all when fundamentally the school was not			
meeting his needs. It was not doing him any good. Anyway, he is better off at home and			
better out of the school environment. They were struggling with his dysregulation in school,			
and he was very upset a lot of the time. It was actually initially my husband who said let's not			
take him into school. (Kit)			
It was a battle every morning, it was a real battle of wills which was exhausting for both of			
us, and I just decided I couldn't fight the battle anymore. We did have 1 or 2 terms where			
she went to school very little, and I became almost a full-time teacher. (Merritt)			
CAMHS said he's not allowed to go to school, but he is starting out of school tuition next			
week. (Kingsley)			
My 15-year-old eldest is not able to attend school and has a couple of hours education			
provision that he manages during the week but its online from home. He has a diagnosis of			
autism, ADHD, depression, and various other comorbidities. (Eversen)	7.1		
My sons' education [is the greatest challenge]. (Kingsley)	Education		
	concerns		

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I worry for Jack and I worry about where he is going to go for secondary school,			
because they're both at private school now, which has small class sizes and everyone accepts			
him there, you know, his quirkiness I worry about him going from a private school to a			
large state school the fact that he could be bullied, and he won't understand why			
he's getting bullied. (Honor)			
People have expectations of him, and sometimes they're too high and sometimes too low,			
so that's really difficult. (Callaway)			
I don't actually know what it's gonna look like, particularly for Poppy, and her exams.			
(Briar)			
It's just you can choose with online whether you're engaging or not, and I like the fact that I	Social media	Social media	External
can almost voyeuristically go and read stuff, and there's no requirement for me to join in	support, advice		factors
that conversation. I can just look at it. It creates an unpressured space for me. (Briar)	and information		
I'm in a lot of Facebook groups, but I would say that for me, they're more about finding			
information. (Kit)			
Well, my support networks are all on WhatsApp, so I use that a lot either within a group or			
individually with people; I've got three friends who I can go to for help. And do they do			
the same to me, you know, I may WhatsApp just say I've had the most crap day ever, you			
are not going to believe what happened. And so, I use that and find it very valuable, it's not			
as good as seeing the person, but it's a reasonable substitute. (Lexington)			
There's also a parents Facebook group for example in our local area. And if there's things			
that I don't know about or I'm looking for more information then there is that support			
there. (Bellamy)			
I'm on Facebook. There are quite a few Facebook groups in Jersey, there's a couple of			
autism and neurodiverse groups set up quite recently, and they're just nice to be part of, I			
don't ever comment, but people ask questions and people just get together. (Honor)			
with social media, I tend to read, but I don't join in because I don't want to be closely			
involved. There's a group I'm on where they give lots of good tips and there's lots of			
resources, but there are like 30,000 people on there and some people tell the whole story			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
there, but that's not me, I'm not gonna do that. I'm a sort of silent participant in some of			
that, just to get some ideas and tips. (Eversen)			
In fact, it will be better to spend less time on Facebook sites because you just end up	Social media		
reading every story and it can just become almost depressing really with some of the stories	unhelpful		
you read. You just think, wow, I guess we we're lucky then, because I read stuff about what			
some people have been told, and it just makes me more worried. (Kit)			
like I think the parent led spaces tend to be so egalitarian that nobody's in charge of making			
sure discussions don't just go round in circles. But some people obviously find it valuable			
to just sit and moan together, but I would rather find solutions and look for how we can			
move forwards. (Briar)			
I have felt sometimes that I've been a bit too sucked into the Facebook groups and			
sometimes, you know, when you're scrolling through Facebook on your phone and its			
problem after problem, and it can start weighing on you a bit heavy, I've started to silence a			
few groups and ignore them. (Cypress)			
I'm on some WhatsApp groups with other single parents, unfortunately because of my way			
of communicating sometimes people think I'm rude, so I've been removed from certain			
groups that I've found supportive. I find that hurtful. (Hollis)			
If I'm upset about something, I'll just call my mum and they did sort of fill that role	Family support	Support	External
reassurance function. But they're getting older, and I don't want to say they're getting less	variability		factors
useful, but the practicality stuff is getting less there because they can't support in that way			
now. (Halston)			
Parents are elderly and live a couple of hours away, and that's the same with my husband's			
parents.			
I generally just don't feel we have support. (Briar)			
Its badly affected family relationships because until my family really understood that Riley			
was not like any other kids they had met, there was a lot of judgement about me and my parenting and his behaviour. (Lexington)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I don't think she [mother] would really know how I feel or how much I struggle sometimes.			
It's almost sad. (Luxor)			
My mum, and I've got two brothers, but they don't help in that way, they're very busy with			
their own families and one lives 2 hours' drive away. The other is in London, but he's very			
busy as well, so, I don't rely on them for that kind of support. I may tell them what's			
going on but wouldn't expect any sort of practical help. Yea, they're busy with their own			
families. (Callaway)			
My mom lives on the next street, but she's not really there for me emotionally, but she'll			
happily let me sit down and drink a cup of tea, but she doesn't do close help. Oh, and my			
mum's disabled, so she's not really able to come and help. (Bellamy)			
Oh yeah, and my family. So, we'll go back to Dorset to see them for a bit of help and things			
and a bit of a break. And my mum is very good with Monarch [son]. (Cypress)			
My sister in Cheshire and she has us up there when she can. She has a little house in	Sibling support	-	
Anglesey that we go to in the summer holidays, so she is helpful. She has her own life, but	variability		
she still helps, and Riley really likes her, really loves her. So, when I go up there, she makes			
a point of taking him out and giving me some time to myself. She's very good.			
(Lexington)			
It's the same with my siblings, and I wish I had a closer relationship with them. My sister's			
married to a guy who I feel is hostile towards me. So, my sister and I are not very close. I			
just feel actively excluded and not considered, yeah. (Hollis)			
I have a brother and sister, they live in London and we're close, as in, I can ask for support,			
or if we have an emergency situation, and I need them to maybe come down and step in,			
and they can, they will. (Eversen)			
I do have siblings but although if something awful happened, they would be here in a trice,			
we're not in each other's pockets and it would be alien for me to ring up and say I'd had a terrible day because of the children or whatever. (Merritt)			

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
We get together once a week for a dog walk and a moan and we walk the same walk, have a coffee And she's got adopted boys who've all got additional needs. (Arden) I think that kind of talk therapy, really just chatting things through, sometimes helps to come up with a bit of a plan, and also a bit of reassurance. You know that it will all be OK. (Halston) It's like going to see friends, which can be a bit draining to make the effort, but you know when you leave them that although it's maybe been tiring, the boost in energy you get from doing it far outweighs the amount of energy that you have to exert. (Landry) Main thing is that feeling that I am not alone. That It's not just me, especially with the adoption network, all the trials and challenges that everybody has with it, I mean everybody. Sometimes I get useful bits of information, but not masses, but there will be the odd maybe social thing. (Lexington) I have loads of people that I consider to be friends, but I have an inner circle who are really good friends who know all the gory details and of what's going on for me and they're people I could turn to. (Ocean) [Support networks are] Very important, I think, especially on days when I'm struggling. Yeah, it can be a bit of a life saver in many ways, you know, to have somebody just to listen.	Social support - emotional & psychological		
And that's another thing, when you have neurodiverse children, all your friends' become parents of neurodiverse children, and you lose any other friendships that you have. (Landry) The other day at rugby, some parents were comparing notes about like, how their kids were lacking independence and not doing things for themselves. I just sat there, and I didn't say anything, but I thought, wow, you really have nothing to worry about there, but I couldn't say anything, because it would've just brought everyone down. (Kit)	Social support - negatives		
One of the parents is also a SENCO at a school, and she talks to me and tries to help me. (Kingsley)	Social support - practical advice		

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
So, I think having someone to talk to, to try and get down to the cause of the problem has			
been like my biggest asset. (Brighton)			
Having someone to lead me through what to do would have been really helpful. There was			
no sign posting of where to go, where to get help. (Cypress)			
I just want to find out as much as I possibly can, and I try and speak to other people who've			
got the condition or other caregivers and just try and tap into all sources of information that			
I can. (Ocean)			
So, we can say, you know, you need to say to her, are you alright, do you need anything, do you need chocolate, wine, you know? Does she want to come round here like. (Honor)			
I have some friends that live around here that, you know, are people that could go to for help. They would be helpful if I just need someone to pick the kids up or something. (Halston)	Social support - practical help		
I've got a really close friend, and her daughter and my daughter are best friends too, so spend quite a lot of time together. She will look after my daughter when needed. (Kit)			
If there was an emergency, they could look after children or they could have the children			
for a couple of hours if we had to do anything, people who my children would feel secure			
being around, and who I'd feel happy for them to be around. (Luxor)			
when Alan was in hospital, people were messaging me and going hey is there anything we			
can do for you, do some laundry, or some food shopping. (Ocean)			
[Having a ND son] has opened up a whole a whole new population of people to me who I	Social support -		
would never have met, never in a million years have met and some of them are absolutely	reassurance &		
fantastic. (Lexington)	friendship		
I really like my friends, I like my neighbours, I like the community where I live. (Ocean)	_		
We have a kind of community where we are and a supportive group of friends. (Bellamy)			
My children's friends have a lot of understanding about my children, like they are part of us,			
like their parents are too because they see a lot of us. (Brighton)			
I have my friends, but I think it's best not to have too many because you know, I kind of			
have my different friends for different things, if that makes sense. If I just want to shut off,			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I'll probably speak to my old school mates if I want to have a whinge about ***** school,			
and life, I'll talk to other friends. (Honor)			
And with the small community, come networks, you can get. Obviously, you can use your			
own networks, but you can also then tap into other people's networks and that's really powerful and useful. (Aden)			
When the older one was running away, and we didn't know where he was, I told my boss, and he was so supportive. (Honor)	Social support in the workplace		
Yes, it's [work] definitely like my social space, I think. (Arden)	•		
I think also that my work helps me, and I can go into work and my colleagues get me			
and get my problems and they can give me time and we can talk. And that helps me a lot.			
(Luxor)			
So, from like a stress point of view, I actually think work can save you a lot of the time			
because it's time that I get to spend with adults. (Brighton)			
My current boss is a bit of a hero of mine. He's a real family man and he recognises when			
people need support. (Merritt)			
I've got the people I work with for wider support. And because my work supports people			
with additional needs and disabilities, they've all been through very similar things to me and			
there's always somebody I could talk to if I had a specific issue and how I should go about			
it. (Jupiter)			
I've a very understanding boss who will quite happily listen to me going on about things			
and why everything is so stressful for me. That really does make a huge difference for me.			
Yeah, just having these little pockets of support is so important. (Clover)			
And, if we're talking utopian, something that had a physical wellbeing space, where you	Parental wellbeing	Personal	Personal
could, you know, book in appointments, where they could just go over forms and things, a	is needed	wellbeing	factors
place where you were forced to make time for yourself, because I think it's so easy to not			
do that. Wellness, yeah. (Briar)			

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
That's one of the reasons I went to down the mindfulness route, because of the sheer sense			
of exhaustion. It's just like burnout. I had two years where I literally couldn't leave the			
house. I couldn't focus on watching TV. I couldn't read. My brain completely shut down,			
and my legs would give way, all those sorts of things. I think that was just a consequence of			
overload from everything that was going on. (Landry)			
And something that makes me angry is when people say what do you do for self-care? And I once said, a cup of tea on my own and some quiet for 10 minutes. And I suddenly got really angry, and I just thought to myself, my God, is that what my life has become? (Lexington)			
And even our mental health needs are put back because we need to be there for them, and though you might be really upset or need a minute for yourself, if they are going to hurt themselves, you've got to deal with them first. And that sucks up all your energy and emotion. That's what it feels like, day in day out. (Luxor) I've started to be a little better about looking after myself and doing a bit of self-care because you can't pour from an empty pot. (Ocean)			
My mom does a lot. (Bellamy) But my mum gets that the children have different needs, so she can babysit for us, and is happy to do it, even though she's an hour away. She understands that quite often they'll be unmasking when they are with her at her house. (Jupiter)	Carers parents can have positive impact	Positive factors	Personal factors
So much seems designed to build inequities in the system so that when people aren't educated and they're not able to advocate for themselves, then they miss out. (Briar) I feel certain services are only accessible to people with a certain education. (Hollis) Yeah, I think I'm definitely positive about the future even if I don't know what it looks like. I'll make it work, whatever, even if I have to go and get a lower-level job, whatever I need to do. (Halston) I have plans for certain parts of the day, so like my mornings are planned, and my evenings are planned. But like the middle bit, just isn't. (Brighton)	Personal attributes		

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
We both do the school run, but that's because my husband's job is flexible, and he can			
afford the time to do that. And then he comes back and works after that, or he'll book			
meetings around the school run. (Jupiter)			
Like today, I've got clear outcomes. I need to go to work. I need to come home. I need to cook tea. (Arden)			
[I'm] Taking control and actively saying I don't want any of this to look like that past, so I'm			
gonna use it to make better and different choices for me and my own family. (Briar)			
It's about prioritizing. You know, if things could be pushed back or it didn't matter because			
I'd already planned them in for the following days. (Briar)			
I literally have to have lists, and I've always had lists for everything. (Landry)			
I do about 200 things every day, you know, I get up and it's like, the minibus, we have 5			
minutes before we leave to go to the minibus. Alright, let's just do that e-mail about that,			
or I'll just pay the water bill. I can do a lot of things, and I kind of think that nothing is			
beyond me. (Lexington)			
we probably now have more sort of normal everyday teenage challenges as opposed to the	Situational factors		
ones that go with the SEN territory because they're not now so dependent. (Landry)			
I used to work until obviously like 3 pm, and then I'd go and do the school run and I'd be			
dealing with the meltdowns. Now they don't happen so much, so I can work longer in the			
day, which is really helpful. (Halston)			
Life is a lot easier at the moment, since diagnosis and medication. (Landry)			
I mean realistically, being comfortable financially is a big positive too. (Briar)			
Everything that we've done so far has been on a private basis at great cost to us. Both			
children have been diagnosed as autistic privately, and we recently saw a psychiatrist for my			
son's OCD, because he has been held up with CAMHS. (Lexington)			
I've been working from home for a couple of months, so that's been much easier.			
(Lexington)			
Childcare help is very limited for him, so that restricted what I was able to do. (Bellamy)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
He has a very strict routine for himself, his reading practice, he likes to set a timer and do			
18 minutes of reading a day. He gets panicked if he can't do his reading. (Hollis)			
We have a very set routine in our house because they need stability, a routine that doesn't			
change because if does, they're dysregulated and everyone's really stressed if something's			
different, so everybody knows where everybody's at. (Jupiter)			
He's at a brilliant school. I'm very lucky that he's there because it's all free, and the local			
authority pay, even though it's an independent specialist school. I have seen him in just two			
and a half terms developing and maturing, that gives me hope. (Lexington)			
Yeah, we're lucky we've got enough funding. In fact, I've got more funding than I can			
staff. So, you know, we're really lucky in that respect. Yeah, we've got the financial resource			
to, yeah, to meet the needs. (Arden)			
My husband works from home. I work very part time, so I've got a zero-hour contract	Support factors		
where I work and it's a sessional trainer job. (Jupiter)			
No, he [husband] works from home and goes to Birmingham once a week. But yeah, we're			
both at home pretty much all the time. (Briar)			
I think the charities are a lot better. They seem to be a lot more understanding, but I think			
a lot of charities employ people from a background of what/who the charity represents, so			
they have a lot more understanding. (Brighton)			
the boys are very lucky that there's a couple of charities over the here that are very helpful.			
So, like last night, both kids went surfing with a charity here called Healing Waves that			
provides self-therapy. (Clover)			
My mum is now 86, and she's unfortunately no practical help to me, but as well, she's aware			
of my situation, and it makes her very sad, but she's certainly there at the end of the phone.			
(Lexington)			
definitely, emotional support from my mum, but she does help a bit practically.			
(Callaway)			
We're 5 minutes around the corner from my mum and she has him once a week overnight. (Hollis)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
Then in the evenings, by the time I've got the kids dinner, the boy's father comes home,			
and we both put them to bed. We're have a routine as a family that tends to go alright, but			
not always My husband, he's really good. We have been together a long time and			
support each other and try and allow times to have our own space a bit. (Halston)			
My husband is very good, and he will always stay and help to make sure the kids have left			
the house on time if it has been a bit of a struggle. (Luxor)			
Work keeps me sane, and it gives me something just for me. (Brighton)			
I get a buzz from my job which is looking after people and feel really appreciated and			
important, and I feel my role's important, so that's a bit of a high for me. (Cypress)			
It is incredibly costly, far more costly with a neurodiverse child. For example, we've had to	Additional costs	Additional	
go down the private education route for various reasons and many other things too have	for neurodiverse	challenges	
been very costly. So, we've had times where we had to sell houses, and that sort of thing.	children		
(Landry)			
I'm also autistic. I was diagnosed in 2020. So, I do a lot of self-regulation through using my	Neurodivergent		
phone. I spend a lot of time on social media or playing games on my phone. Yes, just like	parentage		
the kids, basically. (Briar)			
So it's just the exhaustion from constantly having to fight, and it permeates itself not only	Challenges,		
into the outside world, but you, and you're constantly in this fight mode all the time.	demands and		
(Landry)	responsibility is		
When all those little added pressures come in, the negatives are always there, and I can just	stressful		
fall apart. I have to just go and rock in a corner for 10 minutes until I can cope with it.			
(Brighton)			
You end up constantly having to fight, that's the thing. You know, both my children have	Children's issues		
educational and health care plans, but for both, I both had to threaten with tribunals.	can be complex		
(Landry)	r		
I think having someone to talk to. Somebody who actually understands and can potentially			
offer strategies and support, not necessarily to solve the problem. Because I think a lot of			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
people with children, with SEN, it's not an overnight magic wand. It's like fixing the			
Rubrik's Cube, you know, you fix one bit and then the other bit breaks. (Brighton)			
I'm constantly working. I get up and I work, whether it's care or housework or paperwork. I get up and work and I do it seven days a week. (Arden) Well, it depends, but a normal day in term time is waking up at around 6 if I'm lucky. At the moment, when he wakes up, he wants to play a game, and we have to play games with	Days are long and hard work		
all his toys in his bed. He's 12, but he operates as a much younger child, so he has lots of			
soft toys and we must play the same game every day. I have to do everything for him.			
(Lexington)			
I was working full time for a healthcare provider. It wasn't a brilliant job, and it was stressful, but I was paid very well for it. But it was affecting my mental health along with the caring for my children, and it got to the point where if things had carried on, with all the assessments and things that we needed to do, I might have lost my job. It didn't reach that point but I could have, because they weren't very flexible employers. (Luxor) Umm, but I guess it was just building up, and you know it triggers in your record, doesn't it? You have so many sicknesses in so many months. So, they gave me a talk to yeah, they were sympathetic, but they let me know what was happening and what needed to happen. (Cypress)	Employer not always helpful or supportive		
I would say some days, I feel I just can't cope at all, and I just don't feel there is enough time. If I can give myself time, I feel guilty. I would say that if I didn't do my counselling regularly, or take my medication, I probably wouldn't be here today. (Luxor) When I had my little telling off at work, they advised I went to my GP, so I went, and you know, I confessed I was struggling. I was tearful. I was actually really run down. So, I started on antidepressants, and I've been on them since January and I do feel a lot more like myself again I feel more confident, I'm more willing to do things, less wanting to hide away (Cypress)	Mother on medications and therapy		
I would say it's like a heaviness, it's sort of emotional burden. I'm used to. It doesn't keep me awake at night, it's the acute things that keep me awake at night. (Lexington)	Neurodiverse care is challenging,		

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
There is an overwhelming sense of responsibility that you have when you're a career in my	emotional and		
situation and that it's like being a parent to a new-born all the ****** time. (Arden)	exhausting		
You've got to have a level of vigilance, looking out for things all the time. Looking for the			
signs whether it be incidences of possible self-harm, or you know that just their frame of			
mind, you know, what are they going to do, constantly. (Landry)			
We're trying to get her diagnosed with ADHD and have been waiting for three years on a	Presumptions of		
waiting list. (Landry)	neurodiversity		
And you know, you can do all the tests in the world, but I'm the one living with him, so I			
know. He was retested for autism, and just after his 18th birthday, we got the diagnosis that			
he's on the autistic spectrum, which we knew all along. (Ocean)			
And the other thing I'm doing at the moment taking my time, is trying to find childcare for	School holiday		
the summer holidays, which are looming. That is always a total, utter nightmare and I'm	challenges		
spending hours trying to sort that out because Riley's special needs are such that he can't do			
mainstream childcare, but the special needs provision is usually inappropriate for him as			
well. (Lexington)			
I do some of the work that needs to be done, because I can't get everything I need to do,	Time is limited		
done My dream is that I would be on top of things and if I genuinely get unexpected			
free time, I catch up on things. (Briar)			
I think just the lack of time, that there isn't enough time to do everything that I need to do			
in the day. (Bellamy)			
So probably for the last three years my life has completely been around my kids. (Landry)	ND child focus	Child focus	Child focus
because I didn't understand why everybody could not see that his needs were paramount			
and everything else was a very poor second. And it was just an absolute mindset, and it			
wasn't until I just came out it was like I'm not exaggerating. It was like being in some kind			
of coma, and then I came out of his coma and thought, you're sacrificing absolutely			
everything and actually things aren't going to change. You can't make him better, he's not			
even benefiting particularly from all of this stuff, because you really tell yourself he is			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
benefitting, but he's not. And meanwhile your life is falling apart, and you're losing touch			
with people who are really important to you. (Lexington)			
I recently joined a choir just to have something once a week, that was for me, something			
that doesn't involve, is not about my children. It gets me away from things I'm supposed to			
be doing for work or in the house. Yeah, it's just for me. And I think if you've got children			
with long term illnesses, somebody needs to be making you do that, especially if your life is			
busy and you've got other children. (Briar)			
And even our mental health needs are put back because we need to be there for them, and			
though you might be really upset or need a minute for yourself, if they are going to hurt			
themselves, you've got to deal with them first. And that sucks up all your energy and			
emotion. That's what it feels like, day in day out. (Luxor)			
but there are times when it becomes just too much, and I then end up prioritising [ND			
daughter] ahead of the rest of the family. I do know that they are affected by that, but it's			
all I can do at times. (Merritt)			
And, you know, poor old Poppy [NT daughter], she doesn't get a look in. And that's really	[the] Other child		
tough(Arden)	takes second place		
She's [NT daughter] kind of pulling the short end of the stick because obviously her			
brother's needs are far greater than hers. (Kit)			
It's hard for his little [NT] brother seeing other people do things, and asking why can't we			
do that? And why does he [ND brother] get to choose everything, or why do you treat him			
differently to the way you treat me? That's hard for us. (Kingsley)			
And I think because my daughter finds everything in life so easy. It has quite a negative			
impact on the boys because they find everything so difficult. She's fantastic and at only age			
7, she's great at gymnastics and cheerleading, but my boys have never really had that because			
they don't have the same skill sets to be able to stick with something or do something			
she's a really keen gymnast and people want to poach her for competitions and stuff. But I			
can't give her that support because of all the other needs that we've got to deal with. (Brighton)			

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
the focus is very much the challenged child or the children because it's the challenged			
child that's the problem. Yeah, what about the one in the corner? (Cypress)			
I do some of the work that needs to be done, because I can't get everything I need to do,	Need more time		
done My dream is that I would be on top of things and if I genuinely get unexpected			
free time, I catch up on things. (Briar)			
Yeah, more time. It's down to getting more time, which means I've just got to get smarter about the time I have. (Honor)			
Um, it's really hard because I would say some days, I feel I just can't cope at all, and I just	Limited time		
don't feel there is enough time. If I can give myself time, I feel guilty. (Luxor)	limits activity		
Of course, there aren't enough hours in the day, and I suppose I don't get the head space			
and time and so I'm being overloaded. Sometimes, I think I can only do my best, and I've			
done enough, because I haven't got time, and what I can do is good enough. (Jupiter)			
Yeah, I'm part of your process which has no outcome for me. If I say I don't want to participate, they say they'll just withdraw all services. So that is not helpful really, yeah. (Arden)	Professionals can		
It's fighting the systems. If they didn't make it all so hard, things would have been a lot easier. (Briar)	waste time		
You know, people say CAMHS is fit for purpose, but it isn't. Certainly, the educational system isn't fit for			
purpose. (Kit)			
When I have less work, then I will have more time to properly do the home-ed with him.	Time is limited, so	Time	
(Briar)	needs controlled		
I do some of the work that needs to be done, because I can't get everything I need to do	use		
done, because I'm always in meetings. My dream is that I would be on top of things and if			
I genuinely get unexpected free time, I catch up on things. (Briar)			
I do try to squash in probably more than there's hours in the day. (Ocean)			
So, if I had less, less caring responsibilities would mean more time, that would mean things like it would be nice for Jode [partner] (Arden)			
Yeah, a couple of down time hours and then yeah, back to it, which is really why I struggle	Need time for	-	
to meet up with friends because I have got a lovely lot of friends. But I just enjoy being	mental wellbeing		
quiet in the house and just sitting on the sofa. Yeah, I think it's as good as it can be with	mental wendening		
everything. And I have nice down time, yeah. (Cypress)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I have to have a lot of time where I'm doing absolutely nothing because when I'm			
doing things, I'm full on. But then I also need the time to regenerate, so it's not non-stop			
full on. Something safe like watch Netflix. (Briar)			
but work keeps me sane, and it gives me something just for me. So, from like a stress			
point of view, I actually think work can save you a lot of the time because it's time that I get			
to spend with adults. (Brighton)			
I will have like maybe one or two days a month where I just kind of shut everything off and			
I might do something like, you know, doing a Netflix binge and just kind of give myself that			
day because I just feel like I'm at that limit. And I don't want to be doing things when I'm			
feeling that bad. So, I just have a day or two of down time and then get back to it.			
(Eversen)			
I've just started going back to the gym and being able to do things like that because of			
where the kids are now, and I have the time and mental space. (Landry)			
Sometimes, if I feel up to it, I might do some craft stuff, because that just helps my			
mindfulness. It's things I can get flow from; things (that) are not too complicated help me,			
that allow me to just lose myself for a little bit, that really helps. (Luxor)			
I think the feeling the responsibility for managing all the different complicated sort of			
dynamics in our family, and not always being able to put myself first because I know that			
overall, the balance is better. (Eversen)			
it's like on an aeroplane where they tell you to put your own oxygen mask on before you			
put your kids' masks on. Well, metaphorically, I've never done that. (Landry)			
And I have time by myself walking my dog too and that's really important for me.			
(Cypress)			
We have core meetings every month and there are panel meetings, to sort of, look into all	ND care can be		
the issues we're having with my son. So that takes up a lot of my time and affects me	time consuming		
emotionally as well. (Callaway)			
there's a lot of interaction with school, which is good. But it all takes up a lot of my time			
and for example, I have a meeting this afternoon for an hour at school. There's a meeting			
every half term. (Lexington)			

2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
me management chniques		
ort-term proach		
sitive or gative approach	Ability to deal with stressors	Resource situation
gative	e approach	e approach with stressors

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
it's like there's no end to it, and that's when it suddenly hits you. It hit me after 7 years,			
and I suddenly thought gosh, he's not going to get better, and it's not going to be that one			
day it's going to be easier than this. This is my life now forever. (Lexington)			
At the moment I've kind of given up my hopes and dreams because there's just nothing for			
them right now. I think it's mainly having to be at my son's service 24/7, 7 days a week, 365			
days a year. I might get the odd hour here or there, but its non-stop for me. (Kit)			
I'm so stressed and it's such a chronic situation. I feel depressed every day because actually			
I've run out of feelings. I'm a blank. I don't have anger. I can't take the time out because			
I'm autonomous on automatic screening. You're not a person anymore. (Merritt)			
I'm generally upbeat, but with a wee drop of negativity sometimes. (Ocean)	Upbeat or down		
Outwardly upbeat. Inwardly I struggle, and I'm quite like dying. (Merritt)			
We've got what we need, and we've all got each other. You know, I'm quite positive in that			
way, I suppose. (Jupiter)			
It's just that I feel so passionate that I that I could help people, and I know what you need	Sensitivity,		
to do, you know, I know exactly who you need to call, yeah. (Jupiter)	supportive and		
We always try with to make sure our son feels he can come to us if he needs, and we try	sympathetic		
really hard not to overreact, and accept that he's not necessarily misbehaving but actually			
struggling to handle everything. (Kingsley)			
One thing also is that you will always find somebody worse off than yourself, which sounds mercenary, doesn't it? (Lexington)			
Umm yeah, I don't have much left after children and really, at work I have to be a certain			
person, and that then means that I don't have too much left after that. But I try. (Clover)			
And my patience is kind of worn out, so I find it difficult to put feelings before behaviour sometimes. (Brighton)			
[Speaking to GP practice] I just need to come somewhere and pick up this prescription.			
She put the phone down on me, so I wrote a review on Google how unhelpful she was.			
(Hollis)			
I think I'm OK. Yeah. I have enough energy. (Bellamy)	Energy starting the day		

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I'm not a morning person. So, I do struggle to get out of bed. It does take me a little while			
to get going, but yeah, I'm OK. I get up, have breakfast, get out of the house, so yeah, I'm good. (Cypress)			
Well, I wake up with enough energy, but it's more psychological; can I get to the end of the day, not the physical energy? (Lexington)			
I never feel like I have enough sleep and quite often I will have a nap in the afternoon or			
the evening just to refresh myself. (Luxor)			
I get out of bed because I have to. (Kit)			
Very much able to concentrate on complex things. (Halston)	Ability to deal with		
Oh yeah. It's always me who kind of emails CAHMS and the GP and SENco, or his teacher	complexities		
to organise meetings, you know, if I'm upset with something that's happened at school. And	_		
then it'll be me that goes to the meetings at school. Umm, yeah, it all kind of falls on me.			
(Cypress)			
I am at work, but its very situation based. I don't think I'll be able to concentrate on			
anything too complicated at home. (Brighton)			
You know, I'll try to ignore them [letters] sometimes when I shouldn't or just put things off			
because making decisions is difficult sometimes too. It might not even be anything			
particularly tricky; it's just another thing to consider. (Callaway)			
You know, where's his niche in this world? I firmly believe there is one, but we just need	Hope for the	Evidence of	
to find it. Because despite his disabilities, he's actually very capable in a lot of ways and a	future	hope	
very practical young lad who has a very good work ethic. (Ocean)			
He's two or three years behind his friends who are in the second year at university now, but			
we're looking around the universities. He wants to do genetics to perhaps look at			
conditions like Marfan's I want to do a PhD and I've been thinking about it recently.			
(Landry)			
I do jump to the future a lot, but it's never in a good way, It's always in a worry way. So, I			
try as much as I can to live in the present because I think if I go too far, I will get			
overwhelmed again. I have a lot of fear for my children and their future. (Luxor)			

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I have no idea what that means for my children. I worry about all the hate in the world			
my children will manage their own challenges, with the anxiety that Polly's got and with the			
limitations that Suzie has. (Merritt)		_	
Now it's nice, because he he's really coming out of his shell. Now he's much more relaxed	What gives hope?		
now. With his anxiety levels so much reduced, so it's quite rewarding. (Kit)			
The boys aren't much trouble anymore, but they were, back in the day. I don't think I've			
slept all night for 16 years. I'm going to be on the preschool committee and help with their			
SEND stuff for the other children that come in September. Doing things like that, I feel			
like I can be useful. (Jupiter)			
it was stressful before, because now he's (older son) getting a bit older, he's a bit more			
capable of regulating himself and so his world is opening up gradually. We can now go do			
things with the children that previously were quite stressful but are now much more			
enjoyable. (Clover)			
I don't know what we'll do when the kids leave. I don't know how that's going to work. I'm			
kind of hoping we'll just gravitate more to each other because we don't get the opportunity			
very often at moment. (Merritt)	C11.1	A	D 1 - 4 - "
Once I decide I want to do something, or I want something. I get really focused. Yeah, I	Goal achievement	Assessor or	Regulatory mode
think it's kind of having that focus and perseverance really. (Bellamy)	approach	locomotor orientation	orientation
For me, it's just about doing it, and the challenge and learning something new. (Briar) I would do my best to, you know, do it well. But I might shy away from something that I		orientation	orientation
can't finish, or just do part of it, I wouldn't feel that was satisfying. (Callaway)			
I kind of hold a lot in my head of what I need to do. I like to get things done quickly. I			
don't like to think about things for too long and dilly dally But we just needed to do			
something, so we got on with it. I like to do things quickly if I can (Cypress)			
I'd rather do a good job with something than get it done really quickly. (Honor)			
but I need deadlines to focus me. Otherwise, it will always be oh, well, I'll do that			
tomorrow Life will go as it goes, and I take the opportunities presented more so than			
setting goals I kind of like an overall goal - I take steps towards it and then lose it.			
(Brighton)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
It always has been the perfection and the accuracy, but that's what leads to me			
procrastinating a lot. I find it hard to start a job because I know I won't have time to finish it properly. So therefore, I don't start it. (Merritt)			
I generally get up about 5:00 or 6:00 o'clock. I will generally exercise for an hour or so first	Energy		
thing before anybody else gets up. Then I come back, get the children ready I always go	Lineigy		
and exercise, I like to run, I like to cycle, but that's the time when my brain is thinking about			
like what do we need to do today, decisions to make. (Clover)			
overall, I'm quite optimistic and high energy. (Halston)			
I'm always doing things, doing so much and juggling so many things, it's just that my brain			
craves activity. I find it difficult to relax. (Hollis)			
I'm not lacking energy, but I'm not sort of bouncing around all over the walls, So I'd say			
I'm midway. (Eversen)			
On a good day, I'm pretty hyper, but at the moment and for quite a while I've been very			
low energy. (Merritt)			
Oh yeah, I'm used to just getting on and doing it. (Lexington)	Driver or		
I can build this blooming IKEA table, change my lounge, and hopefully that will make me	passenger		
feel satisfied. I don't think it will, but I'm always trying to find better ways of doing stuff.			
(Jupiter)			
A bit of both in a sense, because you just have to make the most of what you've got sort of			
thing. I'm not backwards at coming forward cause if I want something I'll make the effort			
to get it if I possibly can. (Ocean)			
Just whatever happens. I am not a go getter. (Merritt)			
I let life take its course. (Luxor)			
I am hopeless at letting other people do things, I find it really hard when my husband	Controller or		
washes up because it's never done the way I would do it. (Jupiter)	controlled		
I'm a control freak, yes, I am. (Kingsley)			
if it's going for a meal, I would hope someone else will organise it, just tell me what time and where. (Honor)			
I would definitely be happy for a more controlling person in a group to take the lead if she wants to, or if I thinks she's right. (Eversen)			

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
Lots at the same time I guess, but I prioritize I can do important things first, but I	Multitasking		
might have a lot of things in my head that I need to get done. (Cypress)	evidence		
I do them (lots of tasks) all at the same time - tackle them all together. (Kingsley)			
There's lots of times when I've said, oh, no, I can't do that, or I haven't got the time.			
(Callaway)			
I have had to learn to say no to people. (Brighton)			
Shorter term really for goals. (Bellamy)	Short-term or		
Short-term - just addressing the issues that need to be addressed. (Clover)	long-term		
I just live on a day-to-day basis with all of this. (Honor)	approach		
I set myself goals that are long term, but I don't necessarily work towards them, whereas if I			
have a short-term goal, I'm much more likely to work towards it. (Brighton)			
I get really annoyed when I tell the kids to do something in a certain order and they don't	Attitude to time-		
do it, because doing it in that order is time efficient. Everything must be time efficient	use		
because if you don't do that, it takes longer to do. (Honor)			
I hate wasting time. Yeah, it's very frustrating. (Hollis)			
I think I tend to think I gotta do something immediately or the monster's gonna be	Procrastination		
knocking on the door. (Briar)	proclivity		
I like to get things out the way, even if I don't want to do. I just face it head on and get it			
over with. (Cypress)			
I'll try to ignore them sometimes when I shouldn't or just put things off because making			
decisions is difficult sometimes too. (Callaway)			
I'm one of those people who can procrastinate a lot. I do things to a deadline better than			
early on. If I don't have an external motivation, I find it difficult. (Hollis)			
I can't help feeling judged by other people but underneath, like I've got all that like, oh	Approach to		
my God, everyone's looking at me. When people have given me feedback, I've taken it as a	evaluation of self,		
personal attack. (Brighton)	or others		
No, not really, I don't evaluate much really, no. (Bellamy)			
I think I probably did it [evaluate self and others] more when I was younger though. But no, I don't have the capacity to care. Yeah, think what you like. (Clover)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I had a very good childhood, a very privileged childhood really, went on lots of holidays and lots of good experiences. (Halston) I don't remember much of my childhood I just don't have many (memories) But then, I suppose I don't have any unhappy memories of anything. (Clover) My parents divorced when I was five My mother and stepfather separated when I was twelve Looking back, I would say my mum is a narcissist, so she wasn't very considerate of our needs and feelings. (Kit) Well, my childhood wasn't brilliant, and I was domestically abused. My dad physically and mentally abusing my mum, and my brother and me as well. Physical and mental abuse. (Luxor)		Resource passageway	Empowering, opening, limiting, or restricting passageway
I've had really supportive parents who did everything they could for me. (Kingsley) Definitely mum and dad, they've always been there. (Halston) I definitely remember looking up to both my parents as sort of role models as I was growing up and then perhaps not so much family, but friends and maybe some teachers and being kind of inspired by some. (Eversen) My nan, she used to be at home after school to do dinner for us and get us to do our homework. (Cypress)	Influencers and influences		
I think it to be honest, it was pretty damn perfect. (Ocean) I had a lovely childhood, yeah. (Cypress) Negative really, and I don't actually have lots of memories of my childhood somehow. (Briar) But it was probably more negatives for me to think about my childhood and friends. (Luxor)	Positive/negative view of past life		
Not really, I do constantly feel very kind of grateful and lucky (Eversen) I don't think I'd really change a thing. (Ocean) The only thing that could have been different, would be if I'd had a diagnosis of Aspergers say in university, I think that could have helped me greatly. (Kit) I also regret not knowing about autism earlier, because over the years I went through pretty much hell thinking I was a terrible parent, and I was getting it all wrong. (Jupiter)	Changes to past life		

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
My mum lives nearby and she's my closest family. She's quite involved in our day-to-day	Positives now		
lives; we have coffee together and she comes around and helps out. And then I have a brother and sister, they live in London and we're close (Eversen)			
I just started to go to sing with a choir, and that's been really valuable and really important			
to me.			
I'd say my husband, obviously, and my mum and dad. (Jupiter)			
Well, my husband because we're happily married, and I'm generally happy with my life and			
my little boys, and my big boy. (Kingsley) I have my sister who has gone through similar things to me, and we are a good support to			
each other. I think I'm now in a space where I can switch my brain off, whereas I just			
would not have wanted to have done that until verry recently, even if that option had been			
open to me I've probably got three or four friends who completely get it and			
completely understand because they have been through not necessarily the same, but similar			
things. (Landry)	TAT .*		
I feel there are really times where I need some downtime and can't really get it. And I suppose I don't really see how that's going to change in the future either. (Bellamy)	Negatives now		
I was so resentful of my lot as a family. Now I find it stressful. I'm so stressed and it's such			
a chronic situation. I feel depressed every day because actually I've run out of feelings. I'm			
a blank. (Merritt)			
I have had depression on and off for pretty much I would say for 20 years. Last autumn, I			
struggled a lot and was sort of suicidal; thoughts and almost intentions, and I was referred			
to the local mental hospital who wanted me to go in as an inpatient. (Ocean) I am wondering about either occupational therapy [or] just doing HCA work, the	The future		
healthcare assistant roll, because it's just really interesting, and I feel like I've got something	The future		
to offer it. (Arden)			
I will carry on being a mummy and working. Yeah, I'm just quite happy with my lot and			
watching them go through school and juggling everything. (Cypress)			
How are the children gonna look after themselves in the future. Are they going to be able			
to get a job. Are they gonna be living with me till they're 40? And what answer is there if we get hit by a bus tomorrow? I don't have answers for those questions (Clover)			

1st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
I think I've learned a lot about not worrying about how other people think because you do	Influence of the		
feel very judged all the time. Now I think more that it's just us, and that is how we do it.	past on current life		
(Jupiter)			
But for now, I think what helps me is to be grounded in the present and just being really			
focused on our wellbeing, umm you know, so making sure that I'm doing everything I can			
to give both my sons the right opportunity. (Eversen)			
You can determine what happens to you, and if you sit and wait for good things to happen, they probably won't. (Lexington)			
My stepdad, he had a real negative impact on my life I could have been on a very, very			
bad track with my associations as a teenager. I could have been on a very different track if			
I had not met those people who took the time to kind of understand me and sit down with			
me. (Brighton)			
Taking control and actively saying I don't want any of this to look like that past, so I'm	Future hope		
gonna use it to make better and different choices for me and my own family. (Briar)			
My stepdad was not very nice, he was quite violent, and I got like put aside a lot as a child.			
So, I think I've tried to do the exact opposite, and I maybe overcompensate for that with			
my kids. And that's why I like having the extra time with them. (Brighton)			
(I'm) not looking too far ahead really. (Callaway)			
Well, you never know, one day I might get to have my career. I don't know why I want it			
so badly; I just want to be able to feel selfish. (Kingsley)			
At the moment I've kind of given up my hopes and dreams because there's just nothing for			
them right now. (Kit)			
the money would be nice, but probably the time would actually be better, yeah. (Ocean)	Time or money	Mental	Value placed
Time, time is just so scarce. (Lexington)	orientation	approach to	on time
I've never enough time, so more time. (Hollis)		time	
I have to be really honest, with taking the kids away on an expensive holiday, its money, but			
its maybe also where we are now, with things being more settled. (Landry)			
I have to work full time in order to pay for everything to carry on working as it is, and I	Options for		
would have to significantly reduce my hours to qualify for carers allowance or other support. (Clover)	creating more time		

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
because I'm freelance I don't have to take the jobs, but starting out again after so			
long not working, I feel I need to build up my Portfolio of work again (Bellamy)			
We are considering me cutting my hours because I'm actually off sick at the moment and			
part of the reason for that is the level of support I have to provide for our youngest.			
(Merritt)	TI C	_	
sometimes it's nice to have your own space. I'd call it a recharge, probably. Just to get	Use of spare time		
a bit of distance, so I can breathe. (Luxor)			
But, you know, there's always something that needs to be doing, and usually, mentally, I'm quite drained. I've just started going back to the gym and being able to do things like that			
because of where the kids are now, and I have the time and mental space. (Landry)			
often, it's just easier to lie in front of the TV, to be quite honest. (Hollis)			
I've got loads of things I'd like to do with the family, take them to Disneyland, go on the	Use of additional	_	
Eurotunnel and things like that, experiences together as a family, yeah. (Cypress)	money		
Depends how much, so if I were to win the lottery, then I'd just focus on my children,	money		
because my expenses would be met. (Clover)			
It's really boring, but I would probably use it for the children, maybe to buy a few extra			
textbooks for Suzie. (Merritt)			
I think we'd like to move out a bit more into the countryside. Because that for us, that			
would give us space, the kids could have bigger rooms, and we wouldn't have to worry			
about them having meltdowns and upsetting our neighbours. (Luxor)			
A lot of my decisions are about, just scrimping and saving, not even saving, but just getting			
through, you know, getting by. So, more money would sort a lot of things. (Callaway)			
It would be sewing; it's the actual act of cutting and sewing, and getting it finished really.	Use of additional	-	
It takes mindfulness, and you have to pay attention and be completely absorbed in what	time		
you're doing. (Merritt)			
I did have a day yesterday because we do have three hours social care, personal assistance,			
and my husband took my son for a walk after. So, I had five hours not watching over			
my son, and I worked. (Kit)			

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
Probably take myself off somewhere that does really good coffee and take a book and maybe all my studying, and just have that uninterrupted time, that would be my thing. Yeah, probably studying (Eversen) When I've got time, I meet friends and go for walks I might go online, I might read a book, I might do some learning. I have to have a lot of time where I'm doing absolutely nothing. I need the time to regenerate, so it's not non-stop full on. (Briar)			
I like to go for a run. Sometimes I like to read. Yeah, and occasionally try to find time to watch TV, something mind-numbing. (Belamy) I have a really bad habit of sitting on Facebook and scrolling through mindless stuff that I don't need to do. And visit my mom or my friend and have a cup of tea. (Brighton) I like to immerse myself in TV and programs and I can Just forget everything for a while - a film or something that is not hard to watch. Something I can lose myself in. (Callaway) We've recently got a dog, which I've always wanted, it's become my time to go out for a bit of peace, walking around the field I'll see some friends now and again And spending time with my husband alone without the children is lovely, or watching a film in the evening, just relaxing once the children are in bed. (Cypress)	Relaxation activity approach	Time management	Assessor or locomotor approach
I try to be organised, probably from my secretarial background. I deal with all the bills and all the forms to do with Alan's needs. (Ocean) I do about 200 things every day, you know, Alright, let's just do that e-mail about that, or I'll just pay the water bill. I can do a lot of things, and I kind of think that nothing is beyond me. (Lexington) everything is about proactively managing things. So, whenever you're about to do something, you have to almost sit down and think about how it's this gonna play out. (Landry) I guess I'm just one of those people who always has a To Do List in their head and whenever I can, I tick one off. Basically, I may be writing an e-mail to someone while I'm making coffee while I'm packing lunch and whatever. (Kit) I don't so much push myself anymore. I feel like I've got a bit more of a laidback life compared to where I used to be. It's weird to say there isn't much of a drive (Luxor)	Use of time available	Assessment or locomotion characteristics	Time management

1 st Order concepts	2 nd Order coding/sub- themes	Aggregate Dimensions/ Themes	Grouping label
But we have to be pretty organized. We have a diary. We I have lists of things to do. I run	Control and		
with lots of concurrent goals. (Landry)	management of		
I think having my routine is very helpful. You know, we have three parts to the day I	own time		
just try and get stuff done in the mornings and then perhaps I'll rest when I've done them			
I think I just do it automatically. Every child has a job to do every evening anyway, and			
that's on a rota. It's all written up on the wall downstairs and nothing changes, and that			
really helps me keep organised. (Jupiter)			
I have Google Calendar on my phone, and I put things in the calendar to remind myself,			
and I have visual calendars hanging around the house. Like, visualizing fixing the time and			
planning ahead a little. (Hollis)			
[Organising] a friends get together could be me. I can be quite specific about what I want	Activities		
to do and where I want to do it. (Eversen)	organisation		
My sister lives in Rome and she's invited me and mum to go out there I've organised			
the flights, the insurance, the hotel. I've done it all So, I've done it and I'm happy do it.			
It's fine. (Cypress)			
Like we had friends over for a BBQ or something, that would be me that would organise it.			
(Clover)			
I would get somebody else to sort that [a family get together] out. (Lexington)			

APPENDIX X - RESOURCE PASSAGEWAY ANALYSIS

PASSAG	EWAYS	AYS Common elements							
	Overall impact	Early childhood	Later childhood	Early adulthood	Later adulthood	Degree of challenge resulting	Interventions by individual: therapies/me ds	versity	Current life
Arden		Stable family. Sound education. Strong positive mother Downs brother important		Lived and worked abroad - positive experience.	Established community. Partner Friends locally. Positive work-life. Self-worth. Partner 4 years.				Hope. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Acknowledgement of positive background. Positive. Active, exercise, time with partner.
Bellamy		Parents importa Siblings importa supportive. Downs sister im Grandparents in Happy, positive	ant and aportant. aportant.	Long-term friends	Established community. Husband. Friends locally. Mother. Siblings. Positive work-life. Her immediate family.				Acknowledgement of positive background. Active, exercise, time with husband. Positive.

Briar	Undiagnosed autism. Felt she did not fit-in. Bullied. Trauma - close friend murdered. Unsupportive parents. Mother PN depression - participant went into care. Father autistic. Emotional abuse by father and brother. Brother was favoured child. Clinically depressed age 13 - mother refused any treatment.	Raped (when not evidenced). Emotional abuse by brother. Lost 5 babies. Redundancy twice Gave up career for children. Successful career until children. Challenging life in her 20's. Became independent at age 19 to	Emotional abuse by brother. Difficult relationship with brother.	Childhood has affected her all her life. Mentions one friend.	Therapy. Self- understanding. Taking control of her life.	Undiagnos ed autism	Her immediate family is important. Husband support and involvement. Thinking about the future. Seeing the good in her life. Hope. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Actively trying to ensure her children have a positive life and feel valued and useful. Positive attitude.
		at age 19 to take control of her life.					

Brighton	Undiagnosed autism Violent stepfather. Unsupportive Mother. "Put-aside a lot" as a child. Brother 10 years older - never close. Friendship problems at school. Limited academic success.	Poor friendship group in early teens. Negative life-impact of father. Youth group involvement turned her life around. Youth Group leader.	Developed positive attitude, working to understand and address the negatives she had grown-up with.	Unmarried. First child at 21. Split from husband aged 26, the year 3rd child was born. Longstanding understanding friendship group locally.	Personal relationship trust issues - her step-father issues prevents her entering new romantic relationship (would be a step-father to her children). Relationship with her mother is limited and has no emotional component. No close family support available (mother disabled). Still challenged when under pressure.	Her youth club experiences began to change her life positively in her later teenage years. She has carried on addressing her issues throughout her life.	Undiagnos ed ADHD.	Uses her negative experiences of her father to be positive now for her own family. Sees the positives in her life now. Actively trying to ensure her children have a positive life and feel valued and useful. Uses her past and her positive later life experiences to better understand and help others in her work role. Positive attitude. Is focussed on her children, spending time with them, and building her life and career around them. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Believes she has ADHD - awaiting assessment. Worries her son will become a problem child like she was as a child.
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Callaway	Parents important influence. Father died during childhood. Brothers 5 years older not close. Brothers 'quite bullying'. Brothers negative influence on her. Did not enjoy school. "Life was OK".	Mother important influence.	Mother important influence.	Mother important influence.	Dwells on negative memories. Submissive. Limited hope.	Reliant on her mother for practical help and emotional support. Extensive support networks. Close relationship with her ND daughter. Poor relationship with her son.	Reliant on her mother. Avoids challenges and complex issues. Comments associated with being passive, resigned, and fatalistic.
Clover	No unhappy memories of childhood. Doesn't have many memories. Father worked away. Raised by mother. 3 siblings. Grandfather influential.	University. Grandfather influential.	Postgraduate. Marriage. Home building. Children.	Successful at work. Positive at home.			Children seen as the key positive influence in and on her life. Says it's all been pretty good so far and wouldn't change anything in her life. Acknowledgement of positive background. Active, exercise, time with husband. Positive attitude and approach to life and family. Positive about her work and employer. Proactive, takes the lead. Hope for future.

Cypress	Stable family. Close family. 3 sisters. Mother and father positive presence. Grandparent presence. "Lovely childhood".	Teenage "rebel". Grandparent presence.	Career development.	Career contentment.	Concerns about one son's behaviour in teenage years.		Her immediate family is important. Husband supportive and involved. Hope. Positive. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Actively trying to ensure her children have a positive life and feel valued and useful. Acknowledgement of positive background. Good relationship with children. Active, exercise, time with husband. Social networks.
Eversen	Stable family. Fine, unremarkable childhood. Privileged. Close family. Brother and sister close. Mother and father positive presence.	Decent education. Looked up to teachers.	Career.	Career contentment.		Attending community therapy group. No desire/need for therapy sessions.	Parents are role models. Grateful and feels lucky for her upbringing. Brother and sister close relationship - supportive but not geographically close. Lives near mother who is practically and supportive. Positive attitude. Hope. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Acknowledgement of positive background. Good relationship with children. Social network. Walks, doesn't run.

Halston	childhood. Privileged childhood.	Supportive teachers. University change positive.	Meeting husband. Marriage. Partnership. Children. Positive.	Fairly positive.		Good relationship with husband. Good family networks. Parents and sister close and supportive. Social networks. Positive. Hope. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Acknowledgement of positive background. Good relationship with children. Self-confidence. Walks.
Honor	childhood. Private education.	Less close to brother. Grandfather positive presence.	Straight to work after A levels, by choice. Degree later at work. Professional qualification.	Successful career.		Positive childhood memories. Positive outlook. Good relationship with husband - shares responsibilities. Very happy with her life. Hope. Exercises. Good relationship with children. Self-confidence. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing).

Hollis	Parents arguing. Stressful. Believes parents autistic. Undiagnosed autism. Family holidays. Brother and sister. Felt excluded Grandmother depression. Emotionally distant grandparents. Bullied at school. Cared for younger siblings whils parents worked. Responsibility for siblings.		Social butterfly. Son donor conceived. Good early career. Part-time work after child. Psychological issues as single parent. Social services involvement. Depression. Counselling. Relationship problems. Anger management. Lost jobs. Withdrawal and non- engagement.	Relationship issues. Lost jobs. Withdrawal and non-engagement.		Therapy. Mediation.	Autism.	Not close to sister. Brother withdrawn from her. Not in relationship. Had relationship, broke-up 12 months ago. Relationship problems. No social network locally. Plan to move in with her mother. Mother supportive but lacks empathy. Claims long-term friendships. Speaks to aunt on phone. Says she is happy with her life. Says close to her son.
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Jupiter	Close family childhood. Local community. Stable happy family. 4 close siblings. Mother and father positive presence. Grandparents positive presence. Younger sister died during childhood.	Good teenage years. Adult support external to family. University - changed courses and college.	Married after college. Set-up first home. Children.	Followed husband's career. Career to fit following husband and 5 children.		Good relationship with her supportive husband. Parents still involved, supportive and involved. Active life with external interests. Close relationships with 4 siblings. Social support networks active. Happy with her career. Very happy with her life. Hope. Exercises. Good relationship with children. Self-confidence. Developed a backbone. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Walks for exercise. Socialising.
Kingsley	Parents divorced when 3 years old. Poor relationship with stepmother. Half-brother - no comments. "Everything was fine". "I had a great childhood really".	Poor relationship with stepmother. Was an awful teenager. Supportive parents. No negative comments.	Improved relationship with stepmother. Her husband a key influence. First child aged 19. Married aged 27.	Career.		Good relationship with supportive husband. Social networks - understanding and supportive. Good relationship with children. Positive. Hope. Eudaimonism (personal fulfilment, realising potential and wellbeing - contributing). Her parents have been a model for her family.

	Supportive parents.						
Kit	her parents are neurodiverse. Considers mother a narcissist - not responsive to her needs/feeling s.	Referred to a social worker at age 16. Moved from parental home and elf-caring by age 16. Grandmothe r key person. Had close friends.	Has been "uncomforta ble" all her life.	Struggled with imposter syndrome. Positive about her work.		Self-identified with Aspergers.	Self-identified with Aspergers at age 33 (12 yrs. ago). Waiting for Aspergers assessment. Not very close to her family - geographically or emotionally. No family support noted. Positive about her work - first time working in a group. Recently joined a sports club - enjoys team spirit. One close friend lives abroad. Sports practice.

Landry	Believes both	Father	Successful	Took control	Has had	"Recently"	Her father was her main support, not
	her parents	important	work career.	of her life.	mental and	diagnosed	her husband.
	are	figure.			physical	ND.	Mutually supportive with sister.
	neurodiverse.	Missed			health issues.		3 or 4, or 6 or 7, close friends who
	Parents	schooling					understand but are not nearby.
	arguing.	caring for					Supportive husband.
	Stressful.	mother.					Good relationship with children.
	Parents	School					Positive attitude.
	separated	unsupportive					Hopes and plans for self and children.
	when se was						Eudaimonism (personal fulfilment,
	7.	Mediocre					realising potential and wellbeing -
	Father	success in					contributing).
	volitive -	school.					Exercises - gym and walks
	smacked her a	Not qualified					Mindfulness training.
	lot.	for					
	Lived with	university.					No local friends or social networks.
	mother -	Has carried a					Difficulty socialising since moving home
	became carer	childhood					(geographically).
	to mother	behaviour at					Father died 8 years ago.
	and sister.	age 15 as a					
	Ran the	burden all					
	home.	her life.					
	Mother	Mentioned					
	migraines in	being offered					
	bed at least a	help when					
	week each	she was					
	month.	young, but					
	Mother	not what for.					
	unable to						
	cope, had						
	mental						
	breakdown.						
	Suicidal.						

Lexingto n	Little mentioned. Close family when young. 2 sisters, 1	Negative view of secondary school. Father a key	University positive. Boyfriend. Never recovered	Married age 40 - disaster. Failed IVF. 2 miscarriages. Successful		Family no longer close, but she speaks to all. 2 friends close by. Son is important to her.
	brother.	individual in her life.	from impact of father's death when she was 28.	career.		Difficulty with personal relationships. Limited social life. No sense of local community. Struggles with hope. No evidence of taking time for herself.

uxor	Father had	Mother left	Going to	Took control	Antidepressant	Negative memories of childhood.
	depression.	father when	university	of her life.	s since	Depression and anxiety.
	Father	11.	was		university.	
	physically	Lost friends	positive.		Therapy during	Good, solid relationship with her
	and mentally	when	Diagnosed		adult life.	supportive husband.
	abused her,	moved	depressed			Husband is her partner.
	her brother	from home.	early at			Good relationship with her children
	and her	Did not fit	university -			Friendships, understanding an
	mother.	into new	antidepressa			supportive.
	Brother	school.	nts from			Considers friends her family.
	mental	Some	then.			Uses her negative experiences of he
	health	bullying.				father to be positive now for her
	issues.	Lived with				own family.
	MH	maternal				Sees the positives in her life now.
	problems on					Actively trying to ensure her childre
	paternal side	s for some				have a positive life and feel valued
	of family.	time.				and useful.
	Uncle	Continued				Is focussed on her children,
	suicide.	mental				spending time with them, and
		abuse from				building her life and career around
	Grandparen					them.
	s (mothers	age 18.				Positive attitude.
	side)	Stopped				Hope.
	protective	seeing				Eudaimonism (personal fulfilment,
	when she	father at 18.				realising potential and wellbeing -
	was young.	Mother				contributing).
	Considers	dependency				Exercise.
	grandparents					Time for herself.
	her parents.	daughter.				
	Respect for					
	grandparents	3				

Merritt	Parents divorced age 2. Father sold family home few years later and she moved into maternal grandmother s' home with mother and brother. Brother 15 years older. Strict upbringing with	Loner in school. Picked on a lot. Hated school. Poor performanc e at school. Grandfather key figure. Guide leader key figure.	Good work experience.	Mostly negative memories of her young life.		Depressed recently. Stressed. No social networks. Little hope expressed. Says reaching burnout. Boss at work supportive. Supportive husband.
	grandparents . Lived with grandparents till age 27. Difficult relationship with brother throughout her life. Father was controlling. Believes father was autistic. Little praise from father.					

postOce	Happy, nice	Close to	Close to her		Depression and	Father was role model.
an	childhood.	father.	father.		treatment.	Has been engaged for number of
	Supportive,	Grandmoth	Father		Therapy	years.
	attentive	er	cancer		interventions.	Fiancé is supportive and important.
	parents.	important.	when she			Adores her son.
	Socially	Godmother	was 26.			Friendship with son.
	active	important,	Father			Has learnt from caring for her son
	childhood.	died age 11	stroke and			and is a better person because of it.
	Local	$^{1}/_{2}$.	died.			Social networks.
	community.	Brownies	Depression			Local community.
	Family time,	and guides	on and off			Guide leader - developing others.
	holidays.	significant.	since age			Hope and plans.
	Wider family		26.			Sees the positives in her life.
	-		Son brain			Actively trying to ensure her son has
	grandparents		damage at			a positive life and feels valued and
			age 2.			useful.
	Perfect		Her ex-			Is focussed on her child
	childhood.		husband			Eudaimonism (personal fulfilment,
			distant to			realising potential and wellbeing -
			her and son.			contributing).
			Violent			Exercise.
			husband -			Time for herself.
			sexual			
			assault.			Occasional serious depression issues
			She and son			- last one 6 months ago.
			had to leave			
			family			
			home.			
			Homeless			
			new start.			