

Lost and Found in Transition:

*evolving approaches to enabling young people in complex
circumstances to navigate successful journeys to adulthood.*

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July 2025

A thesis submitted in partial fulfilment of the requirements of Liverpool John
Moores University for the degree of PhD by Published Works.

Acknowledgements

I would like to thank:

My team of Supervisors: Professor Raphaela Kane (Director of Studies), Dr Hannah Timpson and Dr Julie Williams for their warm and constructive advice and guidance during the supervision process.

Professors Tony Long and Alan Glasper, for the kindness, mentorship and critical friendship they offered whilst I was working on papers for publication.

My family, friends, and colleagues for the unwavering support, tolerance and encouragement they have always provided.

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning. Confirmation that I was lead author for the published articles included is provided in Appendix 4.

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Part 1: Lost and Found in Transition: evolving approaches to enabling young people in complex circumstances to navigate successful journeys to adulthood.

Abstract

This thesis integrates my peer reviewed publications, including those based on projects commissioned by a range of organisations. The theoretical concept of *transition* and its application by professional disciplines is critically examined. The *golden thread* acknowledges that as young people progress towards young adulthood, they can frequently fall between gaps in support services or experience poor transition outcomes. This is particularly problematic for young people with long term conditions, disabilities, challenges associated with mental health, neurodiversity, or adverse childhood experiences, and young carers. It may also apply to other groups of young people. Problems occur when service providers consider transition from linear, service-centric or sector specific perspectives because young people experience development across numerous life-course trajectories (sometimes simultaneously).

Two of my peer reviewed publications (Medforth, Timpson, Greenop and Lavin, 2015; Medforth and Rooksby, 2017) evaluate projects which lay the foundations of skills and knowledge in young children which will be useful at later stages of transition (health literacy, learning to navigate and access services, and giving feedback as a service user). Four further peer-reviewed publications use triangulated case studies to explore the transition experiences of young people who face additional challenges; living with long term conditions, disabilities and/ or mental health problems; growing up as “*looked after*” young people; balancing the challenges of adolescence with responsibility of caring for a family member. (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022). Whilst the experience of the young person is central, complementary insights of the young person’s family, practitioners, and professionals lead to recommendations for service development and practice improvement. How these publications are located within the evolving global policy and evidence base is considered in a further publication; a systematically synthesised integrative review summarises research using a range of methodologies and foci on the topic of transition support (Medforth and Boyle, 2023).

The thesis concludes by exploring arguments for a re-conceptualisation of *transition* itself. In my final peer-reviewed publication (Medforth, 2025) I propose a more holistic bio-psycho-

ecological approach which assures the voice of young service users is heard and enables them to contribute to service developments as active citizens. It is possible to integrate globally evolving research, pathways, models, and interventions into the bio-psycho-ecological approach, which will be of interest to an international readership because principles can be adapted to respond to both shared and country-specific challenges, developments and models of service provision as we approach the second quarter of the twenty-first century.

Chapter 1: Background and Introduction

1.1 Transitions and Trajectories: Evolving Theoretical Concepts Rooted in Developmental Psychology.

In this chapter I will critically examine how the concept of transition has evolved and been interpreted and applied to service provision for young people. I will take account of strengths and limitations in different professional and disciplinary perspectives.

Transition is a specific theoretical concept applied to practice in education, health, social care, counselling and psychotherapy and youth work. Elder (1995; 1998) made the distinction between *Transition* and *Trajectory* as concepts: *Trajectory* defines the long- term path of the individual's life experiences in a specific domain such as health and well-being, or education and work, independence and self-determination, or relationships, and family life. *Transition* encapsulates a component within the trajectory marked by the beginning or close of an event, role, or relationship; for example, starting primary school; moving to secondary school; becoming a college or university student, or starting work. Friendships, peer groups, support networks, personal relationships and the identity of the individual may go through significant transitions throughout the life-course (Elder, Shanahan, and Jennings, 2015).

Humans share developmental processes, particularly those which are biologically determined. We are simultaneously influenced by the context within which we develop; family, community, culture, environment, geographical location, historical and political era, society, and life- chances. Leading nineteenth and twentieth century developmental psychologists in Europe and the USA articulated theoretical approaches or attempted testable predictions to explain change throughout childhood and adolescence, sometimes incorporating elements of other disciplines such as biology and sociology to generate new (if not always compatible) perspectives. Initially the focus was on childhood and adolescence, but later development throughout the life-course. Several notable theorists have enduring impact in the twentieth and twenty first centuries and have influenced health, education, and social care practice through application of their ideas despite acknowledged challenges and criticisms (Crain, 2011). Influential examples are briefly highlighted in Table 1.

Table 1: Key Components of Influential Approaches to Explain Children and Young People's Development.

Theorist	Key components of theoretical approach
Sigmund Freud (1900; 1953)	Psychosexual <i>stage approach</i> to understanding how early childhood experiences had an unconscious impact on mental health in later life. Application in psychodynamic approaches to therapeutic work in counselling and mental health interventions. Widely recognised limitations include his interpretative clinical approach, considered by some as inadequately supported by scientific evidence (Bukatko and Daehler, 2004; Crain, 2011).
John Bowlby (1969;1977)	Explored how the development of early emotional attachment patterns during stages of infancy and early childhood played out in later attachment behaviours. Application to the assessment of family attachment relationships made by health visitors and social workers. Widely recognised weaknesses include too strong an emphasis on the mother – child relationship at the expense of the contribution of other care givers and a western cultural bias (Bukatko and Daehler, 2004; Crain, 2011).
Jean Piaget (1952;1964)	Discrete stage approach to understanding leaps in cognitive developmental ability exhibited by children and young people as they progress towards adult thinking and reasoning. Adopted in the early years and primary classroom to support developmentally appropriate learning activity and outcomes. Widely recognised limitations include a sole focus on cognitive development, inadequately acknowledging the impact of the socio-cultural environment. Whilst he recognised the active role children play in their own development, he may have underestimated the cognitive abilities of the young child (Bukatko and Daehler, 2004; Crain, 2011).

Noam Chomsky (1970; 2011)	Proposed a (theoretical) innate language acquisition device in humans and a “ <i>sensitive period</i> ” for learning language in the pre-school and early primary years. Supports the case for early focus on language within the curriculum and early intervention where speech therapy is required. Widely Recognised limitations include the possibility of multiple sensitive periods and the ability to develop language beyond a determined critical period (Bukatko and Daehler, 2004; Crain, 2011).
Lev Semyonovich Vygotsky (1956; 1962; 1978)	Emphasises that social interaction and cultural context are essential aspects of cognitive development and how the child makes sense of their world. Learning is co-constructed through temporary guidance from more knowledgeable others (for example more experienced peers and teachers) who can use cultural tools (language, symbols and technology) to facilitate learning within the child’s Zone of Proximal Development (optimal learning potential). Application in formal and informal education where strategies such as scaffolding learning alongside peers and collaborative activities provide language and culture-rich learning environments. Widely recognised limitations include the un-testability and incompleteness of the theory due to his early death and the possibility that children learn passively as well as actively (Bukatko and Daehler, 2004; Crain, 2011).

Although most of these theorists do not specifically use the term “*transition*” it could be applied to the way they described changes (sometimes smooth; sometimes a significant vault) that the developing child and young person makes between stages. Vygotsky did, in fact, talk about transitions in terms of the child’s progression from dependent to independent learner; from play and imaginary scenarios to real world problem-solving in specific social situations that shape the child’s interactions and learning. Vygotsky

emphasised that during adolescence, through interaction with adults and peers young people internalise social norms and values. These shape their self-concept and lead to the development of higher order learning skills. During this stage interaction with peers leads learning activity, social and cognitive development; speech becomes internalised, and shapes thought processes. Rather than being passive recipients, young people become active users of language and other cultural tools. The Zone of Proximal Development remains relevant as adolescents learn when challenged to slightly extend thinking and learning beyond their current abilities with the support of more knowledgeable individuals. Goggin, Rankin, Geerlings, and Taggart (2016) have, for example applied a Vygotskian approach to supporting students transitioning from high school to university. I, myself observed the value of more experienced peer mentors who, having experienced the young adult carer health champions programme reported in **Article 6**, demonstrated they were supporting the development of knowledge, understanding, self-awareness and confidence of younger carers who were more recent recruits to the programme.

To varying extents these theoretical perspectives are relevant pieces of the incomplete puzzle of an integrated understanding of the transitions children and young people may experience. Applied with caution, and recognising limitations they can help to inform approaches to supporting children and young people to successfully navigate the process. Bukatko and Daehler (2004) reminded us that key questions in developmental psychology remain unresolved, or at least equivocal, requiring critical analysis, evaluation, on-going research, and evidence synthesis:

1. To what extent do nature and nurture influence development?
2. How active a role is played by children and young people themselves?
3. Is development a continuous, gradual process or does it involve significant leaps between stages?
4. How do different domains of development (cognitive; behavioural; social and cultural) interact?
5. How prominent are individual differences in developmental processes?
6. What is the impact of the socio-cultural context?

Theorists are unable to independently provide comprehensive answers to all these questions, but when viewed together they can offer us useful insights. When considered

critically, they can help to progress our understanding. Ferrara (2014), for example, acknowledges similarities and differences between the ideas of Piaget and Vygotsky. Both acknowledge the active role of children in the construction of knowledge, however, differ in how that is achieved. Vygotsky believed that the assimilation of new information does not have to wait for the appropriate level of development, as Piaget argued. Instead, Vygotsky believed this could be achieved through the guidance and instruction of others.

Erik Erikson (1950; 1968) attempted to resolve some of the persistent questions, firstly, by considering the interaction between individual psycho-dynamic aspects and social and cultural contexts on development. Secondly, Erikson introduced eight stages spanning the life-course from infancy to old age. In each stage the individual faces a turning point in their development which requires the resolution of an internal conflict or dilemma. Ornstein and Lewis (2022) describe two opposing psychological tendencies (one positive and syntactic and the alternative negative or dystonic) acknowledging the importance of how the individual attributes meaning to their own developmental process, shaped and influenced by social and cultural experiences.

A core concept from psychodynamic theory is incorporated – the development of the ego as a mediator between the (unconscious) drives and motivations of the individual and the demands of society. If the individual incorporates and develops an ego virtue and strength at each stage, it will provide a stable foundation to support subsequent stages of development and core belief systems about how s(he) relates the self to their relationship with the outer world. Maldevelopment means the sense of self and its relationship to the outer world can become problematic. During adolescence, for example, Erikson saw the challenge to be resolving the conflict of *identity* versus *identity confusion*; the young person reflects upon and evaluates their previous experiences considering societal expectations, establishing their aspirations, core values and “*finding themselves*” (Ornstein and Lewis, 2022).

Erikson’s work has been critiqued because it is largely theoretical, gender biased and inadequately tests cultural transferability (Rose and Robinson, 2006). Others reject the “*storm and stress*” characterisation of the teenage years as un-representative of the experience of most young people (Rutter, 2008). Despite limitations, Rose and Robinson (2006) argue for a dialogic space to consider Erikson’s psychosocial theory of identity

formation when exploring relationships between identity, agency, power, and the cultural worlds of practice.

Erikson provides useful insights into understanding transitions to adulthood and the associated challenges experienced by young people living and developing in complex circumstances or working to overcome adverse childhood experiences; of particular interest is the resolution of identity and what transition means to the young person's developing sense of self.

Zittoun (2009) and Crafter and Maunder (2012) highlight the Vygotskian perspective that transitions may be inner changes (new beliefs or developmental growth) or viewed from the perspective of a socio-cultural framework which is non-linear and links human thought and action to social and cultural situatedness. This may include *consequential* transitions, *symbolic* transitions associated with *identity rupture* and transitions related to *communities of practice*:

"Life is not a long quiet river...the development of a child or a person is not linear, and cannot be predicted; it also shows that many different ways can lead a person to develop a given skill or understanding...life courses appear characterised not only by the regular and progressive establishment of regularities and continuities, but also, and mainly, by the moments in which these continuities are interrupted, reoriented or challenged (Zittoun, 2009).

Examples can be found in my own work - the consequential and symbolic transitions and those associated with identity rupture in the case studies of young people who had experienced transition to adult services or were in foster care highlighted in **Articles 3 and 4** and transitions related to communities of practice (the Children in Care Council and Young Carer Health Champions) referred to in **Articles 5 and 6**.

Environmental and event determined challenges such as poverty, social deprivation or armed conflict may also impact, whilst global events such as the Covid pandemic may also play a significant indirect part in exacerbating risks during transitions (Mulkey, Bearer and Molloy, 2023). Table 2 provides a summary of complex circumstances which may impact on a young person's transition to adulthood. Bold text indicates groups specifically referred to in my peer-reviewed publications. It is important to remain mindful that young people in

these groups will share some challenges with others within their group, some with other groups and have others which are specific to themselves.

Table 2: Examples of complex circumstances which have the potential to impact on a young person's transition to young adulthood.

Disability.
Special educational needs.
Long term or life-limiting medical condition including mental illness and/ or substance misuse (young person or within family).
Neurodivergence.
Young carer/ young adult carer of family member with long term health problems.
In care of local authority , care experienced, leaving care or specific circumstances that raise safeguarding concerns (physical, emotional or sexual abuse, neglect, domestic violence, criminal or sexual exploitation, modern slavery or trafficking, forced marriage, female genital mutilation, honour-based crime, missing from home).
Experience of discrimination (race, gender identification, sexuality, religion, ethnicity).
Lesbian, gay, bisexual, transgender, gender questioning.
Not in education, training, or employment.
Young (unaccompanied) asylum seeker/ dominant language of country of residence is additional to first language.
Family living in temporary accommodation / young person at risk of homelessness.
Family breakdown/ divorce or separation involving unresolved conflict/ bereavement/ loss of a parent.
Experience of bullying.
Young person is offending or in custody, or a parent or family member is in prison.
Teenage parenthood.
Poverty, social deprivation, social or geographical isolation, and other unfavourable health determinants.
Community affected by global events (pandemic, public health, climate change or events, natural disasters, armed conflict).

It is also important to exercise caution to avoid negative stereotyping (it is the circumstances, not the young people that are complex, and challenging circumstances do not necessarily mean pre-determined negative outcomes.) Researchers remind us of progress in our understanding of neuroscience and that developing brain architecture suggests significant negative effects on the hard wiring of the brain occur when a child is growing up in adverse circumstances, but this does not necessarily pre-determine future life

chances and experiences. Young people “*pushing harder against a closed door*” can, with appropriate support, develop the resilience and coping skills required to overcome additional challenges (Shonkoff, et al., 2022; National Scientific Council on the Developing Child, 2004; Center on the Developing Child, Harvard University, 2024).

1.2 Evolving Conceptual Frameworks: Real World Application and Professional Discourse.

Practitioners and researchers have applied the concept of *transition* to significant changes the child or young person experiences as they progress through the education system or how they access health or care services as they develop. The concept itself is undergoing a process of evolution through research or application in various contexts as discussed in the following sections (1.2.1 to 1.2.3) and re-visited in section 4.1. Increasing self-determination as a young person approaches young adulthood remains a key element when *transition* is used by educationalists, health and social care providers, or counsellors and youth workers.

Transition has become a topic of global interest. Research articles and evaluations include work from Argentina, Australia, Austria, Belgium, Canada, China, France, Germany, Hungary, Ireland, Italy, Malaysia, Spain, Sweden, Switzerland, United Kingdom, and United States of America. (Joly, 2015; Zhou, Roberts, Dhaliwal and Della, 2016); **Article 7** Medforth and Boyle, 2023; Sipanoun et al, 2024). The concept lacks a universal definition, often being shaped by the theoretical lens, research orientation, practice traditions, professional discourse, or world views of those who seek to apply it. This is problematic because it leads to a fragmented view of transition, which in practice often means that young people experience gaps in transition support services (particularly where a more holistic, integrated approach is required to respond to complex circumstances and experiences).

1.2.1 Transitions in Formal and Informal Education (School, Youth and Community Work).

Educationalists in the United Kingdom define developmental transitions from birth to five years and beyond (a process, rather than event) placing vital importance on the individual young child feeling “*known*” and valued. Some children are particularly vulnerable during transition points (Table 2) but providing opportunities for professional dialogue enables key people to make essential connections to support children through the process (Dwyer and Wynn, 2002). This conceptual construction, influenced by early developmental psychologists, begins when moving from the Early Years Foundation Stage encountered in

nursery, to Key Stage One when the child starts primary school (Department for Education, 2023). Transitions continue throughout the child's journey through primary and secondary school (years one to 11). Further transitions occur as young people go on to further and higher education.

Using age-defined key stages makes problematic assumptions of uniform developmental experiences and universal curriculum-based outcomes which may under-emphasise individual differences and circumstances. Furlong and Cartmel (2007) highlight problems with such an approach; children from disadvantaged families are often not prepared to cope with the demands of school, nor are schools or classrooms prepared to cope with the demands of the child. This can be the start of a downward spiral to failure. Other influencing factors include the child's relationship with the teacher and cognitive readiness to adapt to the classroom; family disadvantage; the quality of the parent-child relationship; how well the child has had opportunity to develop a wide range of competencies during the early years; their feeling of confidence, level of motivation and ability to achieve within school. The child's characteristics, anxiety and stress can impact their school transitions and success (Furlong and Cartmel, 2007).

Viewed through the lens of Youth and Community Work, transitions are recognised to be non-linear and complex, shaped by a range of factors. Personal situations, social class, geographical locations; education, employment, training, housing, family, income, and relationships interact (Jones and Wallace, 1992; Coles, 1995; Furlong and Cartmel, 1997). Transitions in parallel trajectories do not necessarily occur at the same rate, and young people will experience unequal and diverging paths into adulthood (Jones, 2002). Thompson, et al (2002) emphasise *critical moments* shaped by family, wellbeing and illness, education and rites of passage and wider social and cultural environments. Citizenship, leisure, consumption, geography, and relationships interplay to make transition an individual experience. *Critical moments* as a concept are problematic, implying that the transition is an event rather than a process, however Thompson uses the term to emphasise the *significance* of the young person's experience, acknowledging the risks, associated uncertainty, and complexity of inter-connected transitions.

Wynn and Dwyer (2002) highlight that research evidence at the beginning of the twenty-first century indicates new relationships are being forged between young people and education. Globally, increased participation in post-compulsory education, combinations of work and study and uncertain career outcomes have become common experiences. One result is disparity between the defined goals of education and youth policy and the changing priorities and choices of young people: an increasing tension between linear notions of transition, often expressed in pathways and policy documents, and the life experiences of young people in many countries. Four significant themes are emphasised:

1. An awareness of foreclosed options in educational outcomes is a consistent thread.
2. A discernible shift by the end of the 1990s toward more complex life-patterns and a blending or balancing of a range of personal priorities and interests.
3. The need to give '*active voice*' to young people about the dramatic social and economic changes they have experienced which may not be reflected in the rhetoric of policy (Wynn and Dwyer, 2002).
4. Young people's political engagement and participation in this context is a key concern (Furlong, Woodman and Wynn, 2011; de Almeida Alves, 2023).

1.2.2 Counselling and Psychotherapy.

Anderson, Goodman and Schlossberg (2012) revisit Schlossberg's original theory of *Transition* (developed in 1981) from the perspective of providing psychotherapy to adult clients. Practitioners have also used the ideas in direct work with young people (Winter, 2014). Schlossberg emphasises the *meaning* we give to our experience of transition. Changes that alter our lives; relationships with those who are significant to us; our routines and assumptions about ourselves and our lives are more important than the transition event itself.

Schlossberg's model includes understanding and coping with transitions. It distinguishes between anticipated major life events (from leaving school to retirement and beyond) and unanticipated transitions involving unexpected events (for example major surgery, a serious car accident or illness, or a surprise promotion or redundancy). Non-events are also important (not getting the job you applied for; not meeting the romantic partner you hoped to meet; being unable have children; unable to afford retirement) and can also result in

changed relationships, routines, assumptions, and roles. Perception plays a key role - *transition* is only defined as such by Schlossberg if it is understood in that way by the individual experiencing it. Considerations include type and impact of the transition; the context within which it takes place; what triggered it and how it relates to the individuals own “*social clock*.”

Other influencing factors are the extent of control the individual perceives themselves to have; ripple effects relating to other people involved; experiences of coping and how they may modify the situation, the social and psychological resources the individual is able to draw upon and other stressors in the life of the individual (Schlossberg, 1981; Anderson, Goodman and Schlossberg, 2012). The inherent value of the model is its emphasis on how transitions are *experienced*.

1.2.3 Health and Social Care.

The period from conception to a child’s second birthday is crucial to a child’s development (UNICEF, 2017; H.M. Government, 2021). Nurturing emotional attachments, life chances, nutrition, health and wellbeing, environment, social and learning opportunities lay the foundations for subsequent transitions in the pre-school and early school years (explored in 1.2.1 above) and beyond. In the England *The Healthy Child Programme 0-19* is a framework of universal services delivered by Health Visitors and School Nurses to implement evidence-based approaches to pre-conceptual care; promoting child development; improving health outcomes and ensuring that children who are at risk are identified early (H.M. Government, 2023). “*You’re Welcome*” (H.M. Government, 2023) sets quality standards and an assurance framework developed in partnership with young people to establish youth-friendly and accessible health and care services. It acknowledges the importance of changing health needs and transitions, and the need to work across services for provision to be effective.

What transition means to the young person experiencing it, those supporting or facilitating the transition process, and associated outcomes may be shaped by additional challenges; living in adverse circumstances; depending on health services because of a long-term medical condition or mental health challenge; growing up in the care of the local authority because of abuse, trauma or family breakdown; requiring tailored social care and education

support because of a disability or having additional caring responsibilities associated with health problems of other family members.

Young People in the care of the local authority because of child protection concerns have specific provisions under the Children Leaving Care Act 2000 where pathway plans to independent living are required for relevant children aged 16 and 17. Another duty is provision for on-going support through a Personal Advisor up to age 21 (and beyond if required) to provide on-going support regarding general welfare assistance, education, employment, and training and vacation accommodation if in further or higher education.

According to the UK Children and Families Act 2014 children and young people formally assessed as having special educational needs should have an integrated Education, Health, and Care Plan (EHCP) in place. The child's local authority is responsible for developing multi-agency, cross-sectorial plans in partnership with young people and families to ensure a child or young person receives extra educational support and parents and young people have more choice about which school or setting the child or young person can attend. The plans extend into post -16 education provisions.

Providing well-coordinated transitions between children's and adult health services is accompanied by well recognised problems. This is true for young people with relatively straight forward long-term conditions, such as asthma, epilepsy and diabetes. Those with more complex disabilities, life-limiting conditions, and mental health challenges often encounter additional battles (Bratt et al, 2017; Reekie, 2020; Allemang et al., 2019; Camfield et al., 2019; Hilderson, 2015; Jensen et al., 2015; Joly, 2015; Jiang et al., 2021; **Article 3** Medforth and Huntingdon, 2018a). In healthcare *transition* has traditionally tended to be subject to a sector-centric definition, viewed in terms of a single trajectory: the purposeful navigation of a pathway between children and young people's health services to adult-orientated health care systems. This relatively simplistic perspective often means that young people's needs are overlooked or only partially met in practice, despite a plethora of policy guidance (Royal College of Nursing, 2013; **Article 3** Medforth and Huntingdon, 2018a).

It is evident that young people can fall through gaps in service provision, be lost to services or experience poor outcomes of the transition process (Crowley, et al, 2011; Royal College of Paediatrics and Child Health, 2013; Children and Young People's Health Outcomes Forum,

2012; National Network of Parent Carer Forums 2013; Joly, 2015; Royal College of Psychiatrists, 2022). The need to move between health, education, and social care services compounds the situation because significant differences in expectations, style of service delivery and culture are confronted in children's and adult services. The same people who have looked after them for as long as they can remember will have met young people's care needs in children's services. In an adult environment, they may need to consult several new health teams and adult social care services. At the same time young people's own care needs will be evolving, yet often vulnerable or disabled young people may experience rushed transitions, which are stress-full and lead to social exclusion (Caton and Kagan, 2007).

Young people experience significant transition points between health care services, as well as between schools, continuing education, and employment. All can be challenging to navigate, affecting adherence to treatment and retention by services, worsening disease status and leading to poor psychological and social outcomes (Salomon and Troller, 2018; Allemang et al., 2019; Jetha, et al., 2019; Toft et al., 2018; Reekie, 2019; Hendrickx and De Roek, 2020; **Article 7** Medforth and Boyle, 2023). The result can be confusion and frustration for young people, their families and the committed staff caring for them (Care Quality Commission, 2014; **Article 3** Medforth and Huntingdon, 2018a). Consequences experienced by young people and families include fear, a sense of loss or having fallen off a cliff, and frustration at receiving poorer, more disjointed services (Gorter et al., 2015; Joly, 2015; Hayward-Bell, 2016; Gauthier-Boudreault, Couture, and Gallaher, 2017; **Article 3** Medforth and Huntingdon, 2018a).

Challenges are not unique to the U.K. There is a widespread global interest in evidence-based approaches and best practice guidance based on the needs of the young person, rather than on the needs of the service. There are as many different approaches as there are potential applications. Evidence includes clinically orientated projects, as well as those focussing on the timing of, and preparation for transition; perceptions and experiences of transition; barriers and facilitators; transition outcomes. Innovative approaches include a focus on life-skills development, education transitions, social inclusion and employability. More recently emerging themes include special considerations, dealing with complexity, advocacy, participation, autonomy, aspirations, and young people's rights (**Article 7**

Medforth and Boyle, 2023). The quest for successful evidence-based interventions continues (Sipanoun et al, 2024).

Despite recent progress towards integrated approaches (involving multiple agencies and collaboration across sectors) there is still a tendency to consider transition from a sector focussed perspective, or support needs from a medical rather than a social or rights-based working model (Hogan, 2019; Lawson and Beckett, 2021; Adam and Koutsokelenis, 2023). Failure to integrate approaches defeats holism. The Social Care Institute for Excellence (SCIE) for example, emphasise transition between sectors, only briefly mentioning young people's developmental transitions. They acknowledge that despite many previous attempts in policy and practice to improve the co-ordination of care, examples of "disputed responsibilities, delays, hand offs, 'cost shunting' and 'turf wars' is evident." (SCIE, 2024).

Linear approaches continue to be prevalent despite recognised limitations. The UK National Institute for Health and Care Excellence (NICE) recommended the traffic-light based, three-stage *Ready Steady, Go!* model as an example of current best practice (NICE, 2017). Rogers, Brookes, Aizelwood, and Kaehne (2018) advocate an alternative *10 Steps Model*. NICE updated their standards for supporting young people's transition to adult services in 2023:

1. Young people who will move from children to adult's services will start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
2. Have a coordinated transition plan.
3. Have an annual meeting to review transition planning.
4. Meet a practitioner from each adult's service they will move to before they transfer.
5. Young people who have moved from children to adult services but do not attend their initial meetings or appointments are contacted by adults' services and given further opportunities to engage. (NICE, 2023).

Together for Short Lives (2024) highlight the need for services to keep pace with the growing population of young people who have life-limiting conditions and are living longer with increasingly complex health challenges. Palliative care will be a key part of their experience of transition to adulthood; what is most important is that they can live well and to the full.

The *Stepping Up Pathway* provides a generic framework that can be adapted to plan multi-agency services for individual young people with life-limiting or life-threatening health conditions as they are moving into adult service provision. Multi-agency working involves services in the statutory, voluntary, and independent sectors, as well as those employed directly by the young person and their family through direct payments. The pathway is offered as an overarching cross-agency transition framework that can be used in conjunction with other pathways and guidelines developed for specific conditions or settings (Together for Short Lives, 2024).

Progressing to more holistic, integrated approaches to transition planning raises numerous challenges currently only partially met (if at all); novel approaches to service commissioning; reconfiguring service design; changing professional mind-sets to establish new ways of working; ending discontinuity and bridging incompatible models of children's and adult service provision; continuing evaluation and evidence-based development.

The UK health system recently underwent significant transformation, moving to Integrated Care Systems (ICS). This change will have a substantial impact on the health system but will also affect the wider Special Educational Needs and Disabilities (SEND) system, including local authorities, children's and adult's social care, the voluntary and community sector, and education settings. ICSs will adopt the functions and statutory responsibilities formerly held by Clinical Commissioning Groups (CCGs) but will operate at a larger footprint of around 1-2 million population (NHS England, 2024). The UK government acknowledges that continuing improvement is required to provide the right support, in the right place, at the right time for children and young people who have special educational needs and disabilities and/or are neurodivergent. This includes transition and employability support and life chances. (Department of Education and Department of Health and Social Care, 2023; Vo and Webb, 2024). It is too early to establish evidence of the effectiveness of re-structuring, however past failures and reported experiences of families suggest continuing challenges in accessing adequate integrated provision. Navigating services still feels like "*screaming into a void.*" (BBC News January 2025).

In **Paper 6** (Medforth, 2022) I highlighted that the UK Children and Families Act 2014, and the Care Act 2014 emphasise the rights of young carers to an assessment of their needs for

support and the right to have their views heard and responded to. A Department for Education qualitative report indicates, however, that young carers' needs assessments and uptake of services may be limited by parental fears that disclosure to health and social care professionals might lead to repercussions for their family. There is evidence of confusion among both young carers and their parents as to whether children have received their own young carer needs assessment (Clay, Connors, Day, Gkiza and Aldridge, 2016). Those who come from hidden and marginalised groups and young adult carers may be particularly invisible (The Children's Society, 2018; Chickhardze, Knecht and Metzger, 2017; The Carer's Trust, 2019). Young carers and young adult carers have been experiencing intensification of their caring role for some years; many having to spend more time on their caring role as well as having to care for more people. Stress is exacerbated by widespread anxieties about household finances because of the current cost-of-living crisis in the U.K. (Carers Trust, 2024).

To conclude, in this chapter, I have introduced the *golden thread* of my thesis by providing an overview of how the theoretical concept of transition has developed and how it has been applied to several approaches in policy and practice to support children and young people through life-course transitions. I have begun to consider why some of the underpinning theoretical assumptions may be problematic because of widely acknowledged strengths and limitations. Application of professional or sector-centric perspectives on transition support leads to gaps in service-provision and poor service-user experiences, particularly when aiming to meet the needs of young people whose circumstances are complex, or challenges involve multiple trajectories. This raises the possibility, however, of a more successful holistic approach when different disciplinary perspectives are integrated. In the next and subsequent chapters I will proceed to considering how my own peer-reviewed research and the research lenses of others have the potential to contribute to innovation and service development as evidence-based approaches to transition evolve.

Chapter 2: Reflection on Ontological Position, Research Design, Methods and Impact.

2.1 Author Location and Perspective: Pragmatism, Complexity and Multiple Truths in Real World Research.

In this chapter I will reflect on the research summarised in my peer review publications; its dissemination, impact and contribution to the evolving evidence base to support development in transition support for young people whose circumstances are complex.

My interest in evidence-based approaches to enabling young people living with, or within complex circumstances to make successful transitions to young adulthood synthesises and integrates learning from several strands of my professional and academic careers:

1. Experience from my early professional background as a nurse working with children, young people and families who were living with complex and life-limiting conditions.
2. Academic study of sociology, applied and developmental psychology.
3. Research, project work and evaluation through engagement with a wide range of children and young people's health, social care, education and community services. Work at organisational and strategic level included foci on access to and engagement with health services; support for young people furthest away from education, training, and employment; the experience of young carers and young adult carers; the health of young people in the care of the local authority; quality assurance that health services are young person accessible, friendly and responsive to their needs.
4. Insights from experience through working as an advocate for "*looked after*" children and young people and learning support worker for young people with a range of disabilities, neurodiversity, and associated mental health challenges.

My work has incorporated research at various levels of the pyramid of research hierarchy (Murad, Asi, Alsawas, and Alahda, 2016) including case study research and evidence synthesis. My ontological perspective is a pragmatic, inductive approach to the research that acknowledges that when seeking to understand complex phenomena (what and how it exists) there is no single truth. Reality is constantly re-negotiated, and truths develop in context. Services seeking to provide evidence-based support for young people transitioning

to adulthood do so alongside rapid developments, innovations, and an expanding global research base. The epistemological position (what we can know and learn) assumes the best approach is one that contributes to resolving problems or leads to change and positive developments (Crotty, 2003). Service user and practitioner experience can assist us to recognise gaps in service provision and evaluate innovation, contributing to integration and synthesis of research on new approaches (Rorty, 1998).

Dewey (1933) distinguishes between the positive aspiration of establishing *deductive proof* and the *inductive* process of moving from fragmentary details to a connected view of a situation. Parker (2004) reminds us that progress has sometimes only been possible when researchers have broken the rules of accepted scientific study. *Pragmatism* rejects the historical notion that *quantitative* and *qualitative* research is incompatible - the academic community now accepts and values both. Interviews and case studies are useful to closely illuminate the experiences and reflections of research participants. Quantitative approaches such as randomised controlled trials are useful for measuring narrowly focussed outcomes of specific interventions. Through evidence synthesis the researcher distils findings across a range of published projects to establish the fuller picture.

The research question is more important than the methodological approach to *pragmatists* who acknowledge the possibility of multiple realities, thereby encountering the research question as posed at a point in time within the research cycle, or a specific social and ecological context. If we reject the incompatibility thesis in favour of embracing complimentary perspectives research can lead to action, change or problem resolution (Tashakkori, and Teddlie, 2003; Gray, 2019; Kaushik and Walsh, 2019). From this perspective we are asking how a phenomenon is *experienced* (by those who lived it here and now); what are the associated positives and problems; what might be the possible solutions drawing on learning from other approaches; how can actions be taken to achieve them (and ideally how might we evidence the outcomes)?

2.2 Case Studies, Participation and Realist Evaluation.

Case study can incorporate the *symbolic interactionist's* motivation of getting close to people and how they understand their own activities and social worlds and the principles of *realist*

evaluation, which seeks to look beyond surface appearances to discover underlying mechanisms, behaviour, or phenomena (Travers, 2001).

In *realist evaluation* there is acknowledgment that a critical approach to the underlying social and political context is fundamental to understanding the effectiveness of policy and process (Pawson and Tilley, 1997). Key in my work is illuminating the underlying tensions between policy guidance on how to best support effective transitions and established differences in approach to service delivery. As an empirical method *case study* integrates a contemporary phenomenon (*the case*) in depth and within its real-world context (Yin, 2003; Ebneyamini, and Sadeghi, 2018). Yin highlights three key features of case study research which I can identify in my own work:

1. Case study copes with the technically distinctive situation where there will be many variables of interest. For example, the complex individual circumstances of young people and their experience of transition through different models of service delivery in **Articles 3, 4, 5 and 6** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022).
2. It benefits from the prior development of theoretical propositions to guide design, data collection and analysis (case study and participatory research/realist evaluation approaches cited in **Articles 3, 4, 5 and 6** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022).
3. It relies on multiple sources of evidence, requiring data to converge in a triangulating fashion, whilst recognising that when interpreting content data may also diverge (for example in **Articles 3, 4, 5 and 6** triangulating perspectives young people, families, and service providers (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022).

Case study is particularly effective in evaluation projects enabling systematic production of exemplars that contribute to the understanding of a phenomenon or the developing knowledge of a discipline (Flyvbjerg, 2006). This is evident in **Article 3** (Medforth and Huntingdon 2018a; **Article 4** Medforth and Huntingdon 2018b) where case studies highlighted both the positive and sometimes extremely negative experiences of young people. This led to recognition that significant service improvement and development was

indicated and generation of principles for best practice based on recommendations made by young people and families.

Similarly, case studies reported in **Article 5** (Medforth, Evans, Hills, Madden, and Oyston, 2019) highlighted opportunities to improve healthy eating and lifestyles of *looked after* young people moving towards leaving care, by incorporating the perspectives of young people, foster carers, and the manager of an innovative service.

Narratives within case studies empower participants to tell their stories and frame their experiences, as was evident in the evaluation of the national Young Carer Health Champions project summarised in **Article 6** (Medforth, 2022). This project evaluation was consistent with the principles of *Participatory Action Research* which originated in the 1940s, more recently summarised by Vaughan and Jacquez, (2020) and Cornish, Breton and Moreno-Tabarez (2023):

- Including elements of activism (co-creating knowledge for social change) by exploring the developmental journey from young service users to Young Carer Health Champion.
- Involving collaboration within a community; in this case a nationally representative community of young carers and young adult carers.
- Generating knowledge for action through active systematic enquiry; conducting an evaluation of the experience of participating in the national Young Carer Health Champion project.
- Collaborating to envisage and enact emancipating futures by developing triangulated case studies illustrating how young carers and young adult carers had led or championed service developments nationally and within their own local communities.

Triangulation in qualitative research refers to the use of multiple methods or data sources to develop comprehensive understanding of a particular phenomenon (Patton, 1999) and to evaluate *validity* through the *convergence* of information from various sources (Carter, Bryant-Lukosius, DiCenso, Blythe, and Neville, 2014). In the projects summarised in **Articles 3, 4, 5 and 6** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b;

Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022) we were able to gain representative deep insights into both problematic and positive aspects of the transition experience. Combining the viewpoints of young service users, their families, and practitioners generated principles to help advance best practice.

2.3 Ensuring Authenticity, Trustworthiness and that Research is Worthwhile.

Parker (2004) argues that qualitative research should be judged according to different criteria than those such as *reliability* and *generalisability* traditionally applied in positivist research: firstly *Reflexivity* (the research takes seriously a crucial aspect of the nature of human activity and experience); secondly *Meaning* (the way in which meaningful qualities of subjective human experience are represented); thirdly *Specificity* (accounting for the specific limits and nature of detailed case studies and what might be learned and extrapolated for application to wider populations). *Authenticity* is key to assuring the *quality, trustworthiness, and validity* of qualitative research (Seale, 1999). It is one of the three primary criteria used for establishing validity alongside *credibility* and *criticality* (Whitmore, Chase, and Mandle, 2001). The conduct and evaluation of the research must be *genuine, credible* and reflect both the *lived experiences of the participants* and the *political and social implications* of the research; being mindful of privileges of power. Facilitating children and young people's preferred ways of communicating their voices is essential (Christenson and James, 2008; Spencer, Fairbrother and Thompson, 2020).

I have been mindful to minimise my effect as researcher. Collaboration with co-researchers provided assurance. I resisted allowing the aspirations of project commissioners to influence evaluation of findings. Returning case studies, transcripts of interviews and focus groups to participants to confirm accuracy of interpretation prior to inclusion was another way of assuring authenticity and safeguarding against bias. I am confident that case studies cited in my publications accurately reflect the experiences participants wished to share. When conducting group qualitative data gathering exercises, I aimed to achieve *data saturation* (Saunders, et al, 2018), for example by conducting several rounds of data gathering activity until all the participants had exhausted their ideas and had been given unlimited opportunity to contribute **Article 6** (Medforth, 2020).

Research should always be *worthwhile*; an important ethical consideration, alongside others such as *authenticity, confidentiality, informed voluntary participation, consent, safeguarding* and *data protection* (Whitmore, Chase, and Mandle, 2001). The ethics of research projects supporting this thesis were approved by the university following established processes. Ensuring that participants had a voice through involvement, dissemination and publication, and evidence of impact provided assurance research was worthwhile.

2.4 The Challenge of Researching the Voices of Potentially Vulnerable or Marginalised Young People

Arnadottir, Kristinsdottir, Seim and Vis (2023) highlight the numerous challenges in accessing children and young people for research purposes. When considering conducting research with potentially vulnerable young people it can be tempting to shy away or avoid because of fears of doing more harm than good. It is essential to avoid this protectionist impulse, whilst assuring the application of appropriate values, skills and ethical principles if we are to ensure those children and young people's rights are upheld according to article 12 and 13 of the United Nations Convention of the Rights of the Child (United Nations General Assembly, 1989). These rights are firstly assuring children and young people who are capable of forming their own views have the right to express those views freely in all matters affecting the child (the views of the child being given due weight in accordance with the age and maturity of the child) and secondly the right to freedom of expression (freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.)

Hart (1992) developed The Participation Ladder highlighting that progressive participation in this way lays the foundation for the transition from tokenism to citizenship, explaining that

“Young people’s participation cannot be discussed without considering power relations and the struggle for equal rights. It is important that all young people have the opportunity to learn to participate in programmes which directly affect their lives. This is especially so for disadvantaged children for through participation with others such children learn that to struggle against discrimination and repression, and to fight for their equal rights in solidarity with others is itself a fundamental democratic right....The highest possible degree of

citizenship in my view is when we, children or adults, not only feel we can initiate some change ourselves but when we also recognise that it is appropriate to also invite others to join us because of their own rights and because it affects them as fellow-citizens.” (Hart, 1992).

Kirk, (2007) suggests three core ethical issues in relation to conducting research with children and young people: *power relations*, *informed consent* and *confidentiality*. There are also two key methodological issues. One is *epistemological* and relates to the different cultures of childhood and adulthood and the second relates to the *diverse nature* of childhood and adolescence. Kirk provides an overview of the novel techniques and task-based activities that are being increasingly used to establish rapport and as a method of data collection. This is recognised by the U.K. Department for Education in their User Research Manual (2025) for work with young service users. In the manual important considerations are highlighted including working with gatekeepers and responsible adults; ethical considerations; gaining informed consent from young people, parents or legal guardians; safeguarding both young service users and researchers; utilising engaging and developmentally appropriate methods.

In the empirical studies reported in Articles **1, 2, 3, 4, 5 and 5** the voice and experiences of children and young people were central. These studies were conducted once university ethical approval had been gained and included providing written participant information to children, young people, parents, carers and gatekeepers (schools or service providing organisations). **Article 2** was based on written material and drawings on completed children and young people friendly version of the Friends and Family Test questionnaire, so in this case there was no face-to-face involvement. The other projects involved direct face to face work with children and young people to gather data. To safeguard both the young people and myself, despite having DBS clearance, on no occasion was I alone with the young participants.

To gather data for the *Real People, Real Lives* project (**Articles 3 and 4**) young people were interviewed at home in the presence of at least one parent. This was agreed to be the most suitable venue as it did not involve any additional challenging journeys for the families and was where the participants felt most comfortable. The young people were happy to share

their views and experiences in the presence of parents and carers, through semi-structured interviews. All parties understood that triangulated case studies would be constructed combining the voice of the young people with those of parents and practitioners, so I made clear the expectation that individual young people would be allowed to freely and fully share their own feelings, thoughts, ideas until they had exhausted everything they wanted to say. Parental presence was to support at this stage, but they would get chance to share their perspectives in a separate follow up interview. Similarly, practitioners who had co-ordinated transitions were interviewed separately (either in their workplace or university according to their preference). In practice this enabled all the participants to share their own experiences and perspectives without interruption. On reflection, I was able to employ skills I had developed through my professional practice background (establishing trust; asking questions in developmentally appropriate terms; active and responsive listening; summarising and paraphrasing to check understanding). In my view developing these skills is essential if researchers are to effectively engage and interview children, young people and their families. A similar approach was taken to semi-structured interviews with young people, foster carers and the project manager in the *Hearty Lives* project (**Article 5**). In this case participants chose to be interviewed in the offices in which the project was based.

When I gathered data from groups of children and young people the approach was very different, although ethical principles and research values remained the same. It was useful to be actively engaged in activities that were something the children and young people were used to experiencing, so they felt comfortable to share their ideas both with myself and their peers, in the presence of adults (teachers or support workers).

In the pilot phase of the *Monkey's Health Service* evaluation (**Article 1**) myself and another co-researcher attended six primary schools (including a special school) where the project team were to conduct pilot implementation of the project resources in partnership with class teachers. The resources were engaging and involved whole class teaching, videos, small group activities, puppetry, play and a song. We were introduced to the children by the teacher alongside the other health professional "visitors." Our participation in the half day sessions gave us opportunity to both observe and record what was happening in the classroom and get to know and listen to the children in a naturalistic way during activities and play. This broke the ice for us to lead a short 15–20-minute data collection activity at the

end of the morning. As time was very limited and we wanted to enable all the children to participate fully and on equal terms, we placed a generous supply of post-it notes and coloured pens on each of the childrens' tables. We displayed three titled posters on the classroom wall, explaining to the children that we would like them to use as many post-its as they would like (in the time they had) to share their thoughts about the morning. We asked them to respond to statements on each poster by sticking on their post-it notes with their own thoughts and ideas. We explained that there were no right, or wrong answers and classroom assistants were able to help those children who needed support to write their ideas on the post-its. They could use as many post-its stickers as they wanted to. Statements on the posters were *"One thing I liked... One thing I learned...One thing I might tell my friend..."* Examples of things they said they learned included *"So many things...children's assessment unit...what a walk in is...where to go when I'm hurt...how to keep fit and healthy...what to do in an emergency."* Things they liked included *"interviewing the school nurse...young health explorer videos...play, games and activities...the monkey song..."*

Asking the children to identify something they might tell a friend encouraged them to reflect on how they might share their learning. Responses illustrated the potential for even very young children to become peer educators, sharing information on how to access local NHS services, the role of professionals, getting help in an emergency, calling ChildLine, and health promotion messages. We were thus able to include the voice of the children and their reflection on their experience of the project in the evaluation report. During the data collection process, I was aware of the potential power dynamic between myself as an adult researcher and the young participants. It is impossible to eradicate this potential disadvantage to children and young people entirely, however steps to mitigate it include taking an inclusive approach and working with and alongside, rather than researching upon, young participants. Immersion in the classroom activities alongside the young participants was helpful in breaking the ice, gaining trust and removing barriers.

I experienced similar benefits to facilitate data collection by attending a group meeting of the Children in Care Council (**Article 5**) and the third weekend residential Young Carer Health Champions project (**Article 6**). Here the participants were teenagers and young adults, who knew each other well having established relationships over time. Despite varying levels of confidence, they were comfortable sharing their ideas in front of each other and were used

to (and keen to) share their views and experiences. In designing data collection activities, I was aware that the young people may still need some icebreakers to feel comfortable working with me as an unfamiliar researcher. Again, it was useful to have a trusted support worker the young people knew well in the room. Despite not actively participating they provided a reassuring presence. They were also a contact point for follow-up support should any potentially distressing material or safeguarding concerns arise during the data collection activities.

My experience as an educator made me aware that young people's learning styles may differ and that there would be multiple intelligences within the group (Gardner, 1993; 2008). This must be considered to assure an inclusive approach. I was aware, for example that some of the participants might prefer to move around the room, some may prefer to choose background music, some would be strong on reflective intra-personal skills, others more confident in expressing themselves linguistically, whilst some may prefer to express themselves visually. I designed data collection activities which involved all these and found that using creative materials and activities provided young people with a non-threatening vehicle for working together to share their ideas. Examples include inviting the Children in Care Council participants to work in small groups to create a collage in words and pictures to represent what being healthy means to them and using a paper plate to construct and represent a "healthy meal." This could then be used as a starting point to generate further focus group discussion using semi-structured questions and following up themes that the young people had generated.

I did something similar with the Young Carer Health Champions – inviting them to construct an image of a Young Carer Health Champion, which then generated discussion about challenges, strengths, personal development, changes, goals, achievements and aspirations. I was also able to build upon something that they had developed at a previous residential. Each young person has previously made an image of an *"elephant who never forgets"* on which they had written their health and wellbeing goals. We were able to re-visit these and the young people reflected upon and discussed how far they had come in achieving these goals. I concluded the session with a flip chart and post-it session like the one I had used with the primary school children previously. This time I asked the participants to share all their ideas about what it meant to be a Young Carer Health Champion, what they liked about

the programme and how it could be made even better, thereby taking an inclusive appreciative enquiry approach (Ludema, Cooperrider, and Barrett, 2006). I achieved data saturation (at least in this context) by enabling the young participants to use post-its until they had exhausted all their ideas. Engagement in these activities led to some of the young participants volunteering to take part in follow-up telephone interviews.

In the above examples, where qualitative data was interpreted, for example through the construction of case studies, interpreted materials were returned to the participants for confirmation, or adjustment to ensure that they had ownership of material to be included in the evaluation reports and had opportunity to confirm or challenge its accuracy. In one case a parent made some suggested minor adjustments and in another a young person made suggestions to alter the emphasis within the content.

2.5 Integrative Review as a Method of Evidence Synthesis.

It is legitimate (and sometimes necessary) to combine quantitative and qualitative data (Onwuegbuzie et al, 2015; Gray, 2018). Research synthesis is distinct from study-generated evidence, allowing the researcher to review and place individual studies within the context of wider evidence – an essential aspect of scientific endeavour (Cooper, 2017). Grant and Booth (2009) provide a typology of fourteen methods of review, including, for example, Scoping Review, Systematic Review, Narrative and Critical Review. We opted to undertake an Integrative Review (**Article 7** Medforth and Boyle, 2023) because complex phenomena require an approach that combines diverse methodologies to present a comprehensive understanding of complex problems in health and social care service delivery (Broome 1993; Cooper 1998; Greenhalgh and Taylor, 1997). *Transition* is one such complex topic (Joly, 2015; Zhou et al, 2016).

We discovered a wide range of methodologies (systematic review and research synthesis; quasi-experimental studies; retrospective and longitudinal studies; mixed methods; interviews, focus groups and surveys; participatory and co-production projects) exploring various aspects of the transitions young people make when living in complex circumstances (**Article 7** Medforth and Boyle, 2023). Analysis followed established approaches (Clarke and Braun, 2006; Braun and Clarke, 2022; Braun and Clarke, 2023) to interpreting cross-cutting themes in the findings. We applied the 6 – step coding framework for thematic analysis to

identify themes and patterns in the data (Braun and Clarke, 2006): familiarising ourselves with data; generating codes; combining codes into themes; reviewing themes; determining the significance of themes and reporting findings. Throughout the process it was essential not just to follow procedure but also apply reflective and analytical researcher skills (Braun and Clarke, 2022; 2023).

When accepting a variety of approaches, we cannot discount methodological considerations or quality. Whittemore and Knafl (2005) established the acceptability of Integrative Review by improving the process of *data collection and extraction, analysis, synthesis, and conclusion drawing*. To maintain a systematic approach, we followed established methods for framing the research question, (Kahn, Kunz, and Antes, 2003); writing and reporting the review (Broome 1993; Greenhalgh and Taylor, 1997; Whittemore and Knafl, 2005; Cronin and George, 2020).

Integrative review as a methodology is still evolving; a recognised weakness is rigour during the quality appraisal of retrieved articles (Hopia, Latvala and Liimatanen, 2016). We attempted to resolve this by conducting the arduous task of appraising each article using toolkits specifically designed to critically appraise and evaluate the type of research under review. We chose a range of quality appraisal tools with criteria that best fit the methodological approach taken as summarised in **Paper 7** (Medforth and Boyle, 2023).

There is no published consensus on resolution of the quality assurance question in Integrative Reviews. It could be argued that in **Paper 7** (Medforth and Boyle, 2023) we did not achieve unequivocal resolution in our appraisal process, because we did not apply the same criteria to each study. In practice, however, we found that various toolkits accommodated transferable principles for quality appraisal across methodologies combined with discipline specific criteria enabling us to appraise studies on their own methodological terms. The review took stock of a wide range of systematically retrieved and synthesised perspectives and approaches to transition support, demonstrating an evolving picture of evaluated practice, policy, and research and suggesting the direction for on-going service development and future research.

2.6 Publication, Dissemination and Impact.

Pragmatism promotes *equity, freedom, and justice* in the research process, generating practical consequences for society by *creating action*; the researcher, participants, and the research itself can become agents for change (Rorty, 1991). Dissemination creates potential to inform practice, contribute to service development and the constantly evolving evidence base. Modest studies that nudge the boundaries of knowledge are acceptable (Gray, 2018).

Publication involves careful choice of journal for submission, taking account of the published *aims and scope* of the journal, *target audience*, and *guidance for authors*. This meant publication in a range of journals. Peer-review, rejection and acceptance have been useful developmental processes assisting me with concise and impactful communication; appreciating alternative perspectives on my work; understanding whether expected presentation format and standards have been achieved and the ability to accept and respond to constructive criticism.

Impact is a crucial factor when evaluating the utility of research. It can be measured by counting and recording citations, as well as collecting more anecdotal evidence of acceptance, response, or endorsement from intended audiences. To illustrate, the articles *Still Lost in Transition? Article 3* (Medforth and Huntingdon, 2018a) and *Found in Transition Article 4* (Medforth and Huntingdon, 2018b) were based on a project commissioned by a Clinical Strategic Network who wished to learn about how the transition to adult health services was experienced by young service users. The *Real People, Real Lives* project reported triangulated case studies of young people's recent experiences of transition, drawing on insights provided by the young people themselves, their parents or carers and the professionals involved in co-ordinating the transition process. Despite some positive outcomes, there was still much work to be done. We presented a poster based on the project findings at a conference of the Royal College of Physicians. The final report was circulated by the Clinical Strategic Network to stakeholders across the country. Feedback suggested positive responses from service leads and commissioners at regional and national level, with a call to action, using learning to improve services:

“...new models of care provision and new ways of working are essential...all stakeholders to make sure that the challenges set out in *Real People, Real Lives* are tackled and that the experience of transition and outcomes for young people with long term conditions improves” (Tim Mc Dougal, Clinical Network Lead, Children and Young People).

“This is a splendid piece of work, very well done! I have forwarded it, if you don’t mind, to several of my NHSE colleagues...the trick of course, as we all know, is to take your recommendations and translate them into action with all the partners, the Young Person and family being central to this experience.” (Dr Jacqueline Cornish, National Clinical Director, Children, Young People and Transition to Adulthood, N.H.S. England.)

Publication in the Taylor and Francis journal *Comprehensive Child and Adolescent Nursing* (aimed at international professional and academic audiences) enabled scrutiny through peer review. The journal has an improving impact factor trajectory (2.7 in 2023 compared with 1.3 as an average over the preceding five years). Subsequently I was invited to contribute to an internationally established textbook for students of Children and Young People’s Nursing **Supporting Chapter 1** (Medforth, 2019.) In 2023 Taylor and Francis published a special edition of the journal which focussed on transition. I was invited to help the Editor in Chief to source and review articles and to provide a commentary **Supporting Commentary 1** (Medforth, 2023).

My **Scopus Author Profile** can be found at:

<https://www.scopus.com/authid/detail.uri?authorId=56826146900&origin=resultslist#tab=metrics>. At the time of writing, it indicates a modest but progressing contribution to global academic publications and policy reviews. (Average weighted citation impact 0.37 and mapping of publications to 4 of the WHO Sustainable Development Goals) A summary citation table is provided in **Table 3**.

Table 3: Citation Summary as at 30/10/2024 (excluding self-citations) sourced from Scopus and publisher websites:

Article	Citations
Article 1. Nicholas Medforth, Hannah Timpson, Daz Greenop & Rachel Lavin (2015) Monkey’s health service: an evaluation of the implementation of resources designed to support the learning of primary school-aged children in England about healthy lifestyles and NHS services <i>Issues in</i>	Stålberg, A., Sandberg A., and Söderbäck, M. (2018) Child-centred Care – Health Professionals' Perceptions of What Aspects are Meaningful When Using Interactive Technology as a Facilitator in Healthcare Situations. <i>Journal of Pediatric Nursing</i> 43, pages e10-e17.

<p><i>Comprehensive Pediatric Nursing</i>, 38:3, 181-201, DOI: 10.3109/01460862.2015.1049385</p>	
<p>Article 2. Medforth N, Rooksby K. (2017) Enabling Young Service Users to Provide Feedback on their Experience: An Evaluation of the Pilot Implementation of Children and Young People Accessible Friends and Family Test in General and Dental Practices in NHS England South (South Central). <i>Comprehensive Child and Adolescent Nursing</i> 2018 Mar; 41(1):42-57. doi:10.1080/24694193.2017.1316789. Epub 2017 May 1. PMID: 29474801.https://pubmed.ncbi.nlm.nih.gov/29474801/</p>	<p>Adams C, Walpola R, Schembri AM, Harrison R. (2022) Health The ultimate question? Evaluating the use of Net Promoter Score in healthcare: A systematic review. <i>Expect.</i> 25(5):2328-2339. doi:10.1111/hex.13577.</p> <p>Milani, J. and Boissy, A. (2023). Loyalty to Loyalty Metrics: Evaluating the Use of "Likelihood to Recommend" in Healthcare Experience. <i>NEJM Catalyst</i> 5 (1) ISSN:2642-0007.Doi:1-0.1056/cat.23.0251</p>
<p>Article 3. Nicholas Medforth & Elaine Huntingdon (2018) Still Lost in Transition? <i>Comprehensive Child and Adolescent Nursing</i>, 41:2, 128-142, DOI: 10.1080/24694193.2017.1330370</p>	<p>Bekken, W., Borgunn, Y., Soderstrom, S. (2021) "In the Next Moment I Answer, it is Not Possible." Professionals' Experiences from Transition Planning for Young People. <i>Scandinavian Journal of Disability Research</i>. 23(1) 338-347. DOI: 10.16993/sjdr.783</p> <p>Parsons HM, Abdi HI, Nelson VA, et al. (2022) Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs Agency for Healthcare Research and Quality (US); 2022 May. (Comparative Effectiveness Review, No. 255.) Available from: https://www.ncbi.nlm.nih.gov/books/NBK591524/ doi: 10.23970/AHRQEPCCER255</p> <p>Markoulakis, R., Cader, H., Chan, S., Kodeeswaran, S., Addison, T., Walsh, C., Cheung, A., Charles, J., Sur, D., Scarpitti, M., Willis, D., & Levitt, A. (2023). Transitions in mental health and addiction care for youth and their families: a scoping review of needs, barriers, and facilitators. <i>BMC health services research</i>, 23(1), 470. https://doi.org/10.1186/s12913-023-09430-7</p> <p>Turchi, M., Kuo, D.Z., Rusher, J.W., Seltzer, R.R., Lehman, C.U., Grout, R.W. (2024) Council on Children with Disabilities: Committee on Medical Liability and Risk Management. Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth with Intellectual and Developmental Disabilities. Policy Statement. <i>Pediatrics</i> 153 (6) e2024066841 https://doi.org/10.1542/peds.2024-066841</p>
<p>Article 4. Nicholas Medforth & Elaine Huntingdon (2018) Found in Transition, <i>Comprehensive Child and Adolescent Nursing</i>, 41:4, 237-254, DOI: 10.1080/24694193.2017.1323976</p>	<p>Markoulakis R., Cader H., Chan S., Kodeeswaran S, Addison T, Walsh C, Cheung A., Charles J., Sur D., Scarpitti M., Willis D., Levitt A. Transitions in mental health and addiction care for youth and their families: a scoping review of needs, barriers, and facilitators. <i>BMC Health Serv Res.</i> 2023 May 10;23(1):470. DOI: 10.1186/s12913-023-09430-7.</p>
<p>Article. 5. Medforth, N, Evans, J, Hills, M, Madden, H and Oyston, J (2019) <i>Hearty Lives (Liverpool): a case study-based evaluation of a project designed to promote healthy eating and lifestyles in looked after young people</i>. Adoption and Fostering, 43 (1). ISSN 0308-5759 https://www.semanticscholar.org/Article/Hearty-Lives-%28Liverpool%29-a-case-study-based-of-a-Medforth-Evans/95a2de660415df27b7e2462c1ceb9d123625817a</p>	<p>Green (nee Cox), R., Bergmeier, H.J., Chung, A., & Skouteris, H. (2021). How are health, nutrition, and physical activity discussed in international guidelines and standards for children in care? A narrative review. <i>Nutrition reviews</i>.</p> <p>Hurry, K.J., Ridsale, J., Davies, J. and Muirhead, V.E. (2023) The Dental Health of Looked After Children in the UK and Dental Care Pathways: A Scoping Review. <i>Community Dental Health</i>. 40 145-161.Doi:10.1922/cdh_00252Hurry08</p>

<p>Article 6.</p> <p>Medforth, N. (2022) <i>“Our Unified Voice to Implement Change and Advance the View of Young Carers and Young Adult Carers.”</i> An Appreciative Evaluation of the Impact of a National Young Carer Health Champions Programme. Social Work in Public Health, DOI: 10.1080/19371918.2022.2058673</p>	<p>Saragosa, M., Hahn-Goldberg, S., Lunskey, Y., Cameron, J.I., Caven, I., Bookey-Bassett, S., Newman, K. and Okrainec, K. (2023) Young carers’ perspectives on navigating the healthcare system and co-designing support for their caring roles: a mixed-methods qualitative study. <i>BMJ Open</i> 13:12, pages e075804.</p> <p>Jenkins, C.L., Jane Wills J. and Sykes, S. (2022) Involving Children in Health Literacy Research. <i>Children</i> 10:1, pages 23.</p> <p>Stevens, M., Brimblecombe, N., Gowen, S., Skyer, R. and Moriarty, J. (2004) Young Carers experiences of services and support: what is helpful and how can support be improved. <i>PLoS ONE</i>.19 (3) P.E0300551</p> <p>Ontario Young care Givers Association website https://youngcaregivers.ca/medforth/</p>
<p>Medforth, N., & Boyle, C. (2023). Challenges, Complexity, and Developments in Transition Services for Young People with Disabilities, Mental Health, and Long-Term Conditions: An Integrative Review. <i>Comprehensive Child and Adolescent Nursing</i>, 46(3), 180–200. https://doi.org/10.1080/24694193.2023.2245473</p>	<p>Muehlan, H., Alvarelhao, J., Arnaud, C., Cytera, C., Fauconnier, J., Himmelmann, K., Marcelli, M., Markwart, H., Rapp, M., Schmidt, S. and Thuyen, U. (2024) Satisfaction with health care services in young people with cerebral palsy in the transition period: results from a European multicentre study. <i>Frontiers in Medicine</i>.11. https://doi.org/10.3389/fmed.2024.1306504</p> <p>Lancioni, G. E., Singh, N. N., O’Reilly, M. F., and Sigafoos, J. (2024). Possible assistive technology solutions for people with moderate to severe/profound intellectual and multiple disabilities: considerations on their function and long-term role. <i>International Journal of Developmental Disabilities</i>, 1–7. https://doi.org/10.1080/20473869.2024.2303532</p>

2.7 Strengths and Limitations.

No real-world research is perfect, so strengths and limitations should be acknowledged (Gray, 2018). Two strengths of triangulated case studies cited in my publications are, that when viewed together, they offer interpretative insights and thick descriptions gained from a range of perspectives (service user, provider, and family) and consider different trajectories and transition experiences. They are, however, based only on a snapshot gained in time. Peers and readers could level similar criticisms at the pilot evaluations of projects such as the *Monkey’s Health Service Project Article 1* (Medforth, Timpson, Greenop and Lavin (2015) and the *Children and Young People’s Friends and Family Test pilot Article 2* (Medforth and Rooksby, 2017). Longitudinal (qualitative and quantitative) evaluation of enduring outcomes and the impact of any emergent service developments, new research, or

innovations could enhance findings. These limitations are mitigated by the evidence synthesis in the Integrative Review summarised in **Article 7** Medforth and Boyle (2022), where we reviewed a wide range of research foci, methods, and findings.

Alternative approaches to that of *Pragmatism* could also have been considered in relation to empirical data collection, or in similar future research. These would need to share consistent values and benefits and understanding of the nature of knowledge to those of *Pragmatism*. Hales (1997) argues that *Relativism* is one of the most tenacious theories about the truth. *Relativism* refers to the perspective that there isn't a single universal objective truth about a phenomenon; instead, multiple equally valid interpretations and realities exist. As these are shaped by individual experiences, contexts and perspectives *Relativism*, like *Pragmatism*, is ideally suited to qualitative research such as case studies where the emphasis is on understanding individual unique perspectives and understanding of their lived experiences. In both approaches, researchers are required to be reflexive, acknowledging their own biases and how they might influence the research. This is consistent with my goals when developing the case studies reported in **Articles 4 and 5**.

Mertens (1999; 2008) explains that *Transformative* approaches recognise that knowledge is not neutral, but influenced by human interests, reflecting the power and social relationships in society which shape knowledge construction. Mertens proposes the use of an inclusive model of evaluation that can address the tension between what is needed to accurately represent the experiences of marginalised groups research and the traditional canons of research. Values applied include those of explicitly addressing *marginalisation*, structuring studies to be *inclusive* of all voices, recognising *community resilience*. The goal is to develop responses and interventions which support these values by constructing knowledge to help people improve society. Mertens (2023) illustrates this by explaining how a *transformative* lens would lead an evaluator to recognise that basing an intervention on a version of reality that attributed the causes of poor health to bad food choices in food and lack of exercise would continue to support an oppressive status quo. Alternatively, by structuring the evaluation to include all voices, valuing the knowledge and experiences of marginalised communities, addressing power issues and providing safe conditions for data collection can contribute to better and more nuanced understanding of community needs. This can then

be used to develop intervention that has greater potential to decrease health disparities. These aspirations align to my own, for example, when conducting the *Hearty Lives* project evaluation reported in **Article 5** and the evaluation of the *Young Carer Health Champions* project reported in **Article 6**.

In *Qualitative* research good analysis practice requires a systematic and planned approach, which is transparent and leads to valid conclusions. It also involves the researcher interpreting data, so they need to remain aware of their own biases and reflect upon their impact on the process of interpretation. Although *Thematic Analysis* is often used merely to describe or summarize key patterns in data, for Braun and Clarke (2022; 2023) good analysis practice involves more than simply reporting what is in the data; it involves telling an interpretative story about the data in relation to a research question. This involves recognising the plurality and location of approaches. My chosen approach is located towards what Braun and Clarke describe as the *Big Q* end of the scientifically descriptive (*small q*) and the *artfully interpretive (Big Q) analysis spectrum*. This includes both *topic summary* (for example HL or Health Literacy) and *meaning based* interpretative themes (for example LFT or Lost or Found in Transition) (Braun and Clarke, 2022; Braun and Clarke, 2023). This approach is consistent with the value positions and ethical principles identified in Chapter 2 and inevitably involved an element of reflexivity when identifying and reviewing the cross-cutting themes and their significance; a skill Braun and Clarke (2023) suggest is part of becoming a *knowing researcher*. Here I was able to apply reflective and interpretative skills developed through my professional experience alongside my developing research practice. An alternative approach I could have considered is the *realist* approach to thematic analysis proposed by Wiltshire and Ronkainen, (2021). The impact would have been an interpretation based on identification of *experiential*, *inferential* and *dispositional*, rather than *topic* and *meaning* based themes, however in my view the results would have been similar and achieved the same aims; it could be argued, for example that the sub-theme coded as the perception of being lost or found in transition reflects *topic* and *meaning* based themes, but could equally be interpreted in terms of *experiential*, *inferential* and *dispositional* themes.

It is acknowledged that in qualitative research the researcher will inevitably apply a *subjective* lens during the process of identifying and interpreting patterns and themes within

a rich textual data set. My own overriding personal *bias* in the research process is reflected in the stated aims of my work; a desire to enable young people, parents and carers and practitioners to tell their stories and share their real-world experiences and consider these alongside the broader evolving evidence base. I make no apologies for this; however, I did guard against the risk of over interpretation or misrepresentation by returning case studies to participants to confirm accuracy (**Articles 3, 4, 5 and 6**) and working with a co-researcher when quality appraising articles when conducting the integrative review (**Article 7**). Perhaps this is acceptable considering a pragmatist perspective; understanding the possibility of multiple realities and taking the best approach to answer the research question(s) by achieving reflexivity and theoretical rather than slavishly adhering to procedure (King and Brooks, 2018). (This of course would not justify poor practice or failure to be transparent.)

Having reflected on my learning about the research process, in the next chapter I will explore how findings from my peer reviewed contributions align to the wider body of research, learning from triangulated insights, identification and analysis of recurrent themes and evidence synthesis.

Chapter 3: Discussion of Findings: insights, learning and analysis of interconnected themes.

This chapter builds on the previous chapter, acknowledging that it is beyond the scope of this thesis to revisit all findings here. Instead, I will discuss them in terms of broader inter-connecting themes and use these to develop and propose a new conceptualisation of approaches to supporting young people through complex transition processes. To identify cross-cutting themes I re-familiarised myself with the published articles to conduct a process of identifying recurrent concepts, coding, and combining them into themes (Clarke and Braun, 2017; Braun and Clarke, 2021) Themes were determined to be significant if content triangulation (convergence or divergence) was evident across the articles.

Themes explored in greater detail below include *shared challenges during transition and additional complexities*; laying the foundations of self-determination through advocacy and innovation; *young people transitioning to young adulthood in challenging circumstances*; *preparation and readiness for transition*; *perceptions and interconnected experiences* and *service developments, innovation and research*.

3.1 Shared Challenges During Transition and Additional Complexities.

Earlier I suggested that young people confront compounding demands during their transition to adulthood because of complexities associated with their personal circumstances alongside challenges shared by all young people as they approach young adulthood (developing identity and sense of self; evolving relationships; achieving social and financial independence or fulfilling aspirations through education and employment). Geographical location, historical context, policy, and political environment also shape individual and shared circumstances, and experiences.

Young people who have long term or life-limiting conditions and disabilities, or mental health difficulties face additional hurdles because of their medical conditions or because of the need to navigate their journeys through services which may not align or have yet to be developed to recognise and meet their needs. Health and well-being outcomes can be compromised but life chances and opportunities will also be restricted without adequately integrated multi-disciplinary, cross- sectorial approaches. **Articles 3, 4, and 7** (Medforth and

Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Pearson, Watson, Gangneux, and Norberg, 2020, Medforth and Boyle, 2022).

Young people in the care of the local authority may experience rushed transitions, moving towards leaving care whilst at the same time trying to overcome adverse childhood experiences. Developing skills in managing their own health and well-being is essential **Article 5** (Medforth, Evans, Hills, Madden, and Oyston, 2019; Smales, et al, 2020).

Young Carers and Young Adult Carers often encounter additional challenges in managing their own health, well-being, and self-care because of caring responsibilities whilst at the same time acquiring community advocacy skills and championing the needs of young people like themselves (**Article 6** Medforth, 2022). Some challenges will be individual, some will be experienced by young people facing similar problems, and some will be shared with other groups who are marginalised. Health literacy, well-being, adopting healthy lifestyles, and practicing self-care were important to all of groups of young people and families we interviewed and reported in **Articles 3, 4, 5 and 6** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022).

Gaps between policy and the delivery of support services may be localised or country specific, but by no means exclusive. There is a global interest in the experience of transitions to adulthood highlighting the need to develop policy, services, practice and evolving research evidence (including evaluation of innovation in service provision and models to support practice). International research and policy development collaborations are emerging (**Article 7** Medforth and Boyle, 2023; Sipranoun et al, 2024). Perspectives may converge or diverge when viewed from the perspectives of young service-users, families and professionals, service-managers, innovators, policy developers and researchers.

3.2 Laying the Foundations of Self-determination and Citizenship Through Advocacy and Innovation.

Supporting children's transition between developmental stages begins with laying foundations, understanding the self and being known in the early years and progresses to the search for identity during the teenage years. In **Articles 1 and 2** we report evaluations of two innovative approaches which aim to do this in specific contexts. In **Article 1** the project

was a national NHS Institute for Innovation and Improvement programme which aimed to embed teaching resources in primary schools throughout England. The resources were developed to enable teachers to facilitate learning about health and wellbeing; the range of NHS services available, how to access them, and how to seek help in an emergency. If effective the result would be for children aged 5-11 to take a more active role in managing their own health and well-being, improving their health literacy, and determining how they access and use health services. They could also become advocates in their own community by sharing knowledge and understanding with friends and family. In the project evaluated in **Article 2** the innovation involved the piloting of a children and young people friendly version of the Friends and Family Test, which enabled children and young people to give feedback on their experience of using dental and general practice services in a region in the south of England. This gave children and young people an active role in the quality assurance and continuing improvement of services serving their local community; something which previously only adult service users had been invited to do.

In *Self-determination Theory* (Deci and Ryan, 2012) emphasise the importance of intrinsic motivation and of social contexts that support or hinder natural tendencies towards growth and self-regulation. These are innate so we are inherently active or pro-active in seeking the satisfaction of three basic psychological needs: *autonomy*, *competence* and *relatedness*. Autonomy satisfies the need to feel in control of our actions and the choices we make and involves a process of self-endorsement. Competence is about having confidence in our capability to interact with our environment, developing our skills and experiencing a sense of mastery in achieving them. Relatedness is about experiencing a sense of being connected to and belonging the world we live in by being cared for by others and receiving social support; something which is essential to meeting our psychological needs adapting to the demands of our external world, developing a sense of self and identity and fostering positive developmental outcomes (Deci and Ryan, 2012).

Transition towards self-determination is therefore central to achieving developmental transitions along other trajectories and the concept has been applied to supportive interventions in a range of contexts including education (Guay, 2021); health care (Ntoumins et al, 2020); social work (Kirzner, 2023); youth and community work (Jones and Feigenbaum, 2021); sport (Standage and Ryan, 2020); life and employability skills development (Gupta,

Bhatt, Mather and Badge, 2024) and psychotherapy (Roth, Marten and Vansteenkiste, 2019). Application of Self-determination Theory to interventions across a range of contexts and recognition of its consistency with practitioner values within these sectors may be a key to unlocking multi-professional, inter-sectorial approaches to providing transition support that place the young person and their expressed wishes, needs and aspirations at the centre.

Sometimes a key component of laying the foundations of development towards self-determination is having an advocate to support children and young people to voice their own experience of services, and life-course transitions (Okumura, Saunders and Rehm, 2015). At the same time developing self-care and self-advocacy skills and eventually becoming an active participant in a community and becoming a champion for others may be desired outcomes (**Article 3** Medforth and Huntingdon, 2018a; **Article 4** Medforth and Huntingdon, 2018b; **Article 6** Medforth, 2022; **Article 7** Medforth and Boyle, 2022.)

MIND (2024) for example, explain how advocacy (self, family, or community) can be useful for users of mental health services. Self-advocacy is the ability to communicate your needs to thrive in school, work, and life. It can be learned at any age but needs to be underpinned by developing knowledge and understanding of health, well-being, and self-care, rights, and responsibilities and how to access support. This is something which we explored in our evaluation of a pilot designed to teach primary aged children about the range of NHS services available and how to access them – important skills to be developed into navigating services later in life (**Article 1** Medforth, Timpson, Greenop and Lavin, 2015). In **Article 2** (Medforth and Rooksby, 2017) our evaluation found that a Friends and Family test designed specifically for children could enable pre-school aged children upwards to give feedback on health services they experience.

Advocacy was a key theme for young people who experienced difficult transitions and their families who recognised that having an advocate to support others like them is essential **Articles 3 and 4** (Medforth and Huntingdon, 2018a and 2018b). The advocacy role of a Transition Co-ordinator was highlighted in the integrative review summarised in **Article 7** (Medforth and Boyle, 2018). Earnest, Wong, Federico, and Cervantes, (2023) offer a model of advocacy across three domains of influence (*practice, community, and government*) using three categories of advocacy skills (*policy, communication, and relationships*). They suggest that this framework is immediately applicable to a broad variety of health professionals,

educators, researchers, organisations, and professional societies. These elements are evident in practice through the transitions young carers and young adult carers made from service user to citizen and community advocates, influencing at government and policy level as well as in local communities **Article 6** (Medforth, 2022).

3.3 Young People Transitioning to Young Adulthood in Challenging Circumstances.

Effective transition support requires understanding of special considerations to meet individual young people's specific circumstances (social and family context; assets and challenges; resources and aspirations; health, education, medical and care needs). This was evident in both our synthesis of current evidence **Article 7** (Medforth and Boyle, 2022) and our case study-based articles (**Articles 3, 4, 5 and 6** Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022).

In **Article 5** (Medforth, Evans, Hills, Madden and Oyston, 2019) we highlighted how healthy eating and healthy lifestyles were important considerations but often overlooked by social workers planning young people's preparation for leaving care.

Professionals supporting young people need to recognise that transition requires an integrated approach and involves collaboration across sectors to enable young people to make successful transitions. This is no more evident than in the case studies reported in **Article 3** (Medforth and Huntingdon, 2018a) where a young woman with complex health needs and disabilities and her family become lost in the transition process. Significantly poor health, social and educational outcomes result from fragmented or non-existent services, yet successful outcomes can be achieved. In **Article 4** (Medforth and Huntingdon, 2016b) we illustrate how a young man with complex health needs and disabilities finds himself and his place in the community, enabled by a holistic model of transition support and service delivery located in a cross-sectorial hub. Here, a transition team lead timely planning and collaboration between education, health, social care, housing, community organisations adult and children's service commissioners.

3.4 Preparation and Readiness for Transition.

The challenges for service users and providers are not new; researchers, policymakers, commissioners, and service providers have been grappling with the problem of how best to

plan for and support transition to adulthood in these groups of young people for several decades, with varying degrees of success (Crowley, et al., 2011; Children and Young People's Health Outcomes Forum, 2012; Royal College of Nursing and Royal College of Paediatrics and Child Health, 2013; National Network of Parent Carer Forums, 2013; Care Quality Commission, 2014; Joly, 2015; **Article 3** Medforth and Huntingdon, 2018a; **Article 4** Medforth and Huntingdon, 2018a; Zhou, Roberts, Dhaliwal, and Della, 2016; **Article 7** Medforth and Boyle, 2022). This is despite a plethora of policy guidance documents published over the past two decades by organisations such as NICE in the UK as well as professional bodies, third sector and service user advocacy organisations.

Case studies in **Articles 3 and 4** (Medforth and Huntingdon 2018a; Medforth and Huntingdon, 2018b) provide illustrative examples of both where this has been successful and where it has spectacularly failed for young people with long term health conditions and disabilities. In **Article 5** (Medforth, Evans, Hills, Madden, and Oyston, 2019) and **Article 6** (Medforth, 2022) we highlight how health and wellbeing needs to be a key consideration in relation to children and young people transitioning in the care system and for young carers. In **Article 7** (Medforth and Boyle, 2023) we found a consensus in recent international publications that where young people's circumstances are complex, transition planning is best started in the early teens and considered to be a process rather than an event (Dunn, 2017; Hayward-Bell, 2016; Rees, 2016; Peron et al., 2018; Gauthier-Boudreault et al., 2017; Colver et al., 2019; Boyce et al., 2020; Camfield et al., 2020; Hendrickx, De Roek, Mara, and Dielman, 2020). Developmental readiness of individual young people (Peron et al., 2018; Toft et al., 2018) and parental readiness to let go (Allemang et al., 2019; Bratt et al., 2017) will shape the process.

Mental Health is an important consideration and remains problematic or poorly understood partly due to the emergence of mental health concerns during the teenage years (Dunn, 2017; **Article 3 and 4** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Appleton, Loew and Mughal, 2022). Young service users perceived services to be poorly planned and uncaring, prioritising provider convenience over the interests of young people. To minimise serious risks for young service-users improved transition programmes should start no later than fourteen with a clearly documented protocol and plan, supported and

evaluated by strategic level transition reviews across trusts (Dunn, 2017; Hayward-Bell, 2016; Hendrickx, De Roek, Mara, and Dielman, 2020; **Article 7**, Medforth and Boyle, 2023).

Zhou et al. (2016) concluded that readiness for transition should be assessed regularly and accurately by applying validated measurement tools. In **Article 7** (Medforth and Boyle, 2022) we reviewed validated tools and pathways to assist with assessing transition readiness and support the transition process. In **Table 2** examples are aligned to best practice principles emerging through synthesis of recommendations from **Article 3** (Medforth and Huntingdon, 2018a); **Article 4** (Medforth and Huntingdon, 2018b); **Article 5** (Medforth, Evans, Hills, Madden, and Oyston, 2019); **Article 6** (Medforth, 2022); **Article 7** (Medforth and Boyle, 2022).

Table 2: Synthesis Summarising Best Practice Principles and Examples of Supporting Tools.

Emerging Principles for Best Practice.	Tools to support the transition process.
<ol style="list-style-type: none"> 1. Implement a transition programme guided by young people's assets, aspirations, and preferences. Include the promotion of health and wellbeing and how to navigate services. 2. Commission to ensure strategic support and systematically monitor and evaluate outcomes, ideally longitudinally. 3. Provide advocacy and transition training for young people, families, practitioners, and service-providers. 4. Identify a Transition Co-ordinator and successor in case of staff turnover. 5. Begin the planning process as early as possible (ideally around 12 years of age) acknowledging that it may take up to 7 years. 6. Ensure a documented Transition Plan is in place using established models, tools, 	<p>Assessing Transition Readiness</p> <p>TRANSITION-Q - a validated generic scale for use in transition programmes to measure self-management skills in adolescents with chronic health conditions (Klassen et al., 2014).</p> <p>Transition Readiness and Appropriateness Measure (TRAM) was developed, piloted, and validated in partnership with young people as part of the Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare in Europe (MILESTONE) study (Santosh et al., 2020).</p> <p>Transition Preparation</p> <p>Transition Preparation Programme which was asset-focussed and co-produced by young people, mental health practitioners and researchers to improve outcomes and experience (Dunn, 2017).</p>

<p>passports, and technology where appropriate.</p> <ol style="list-style-type: none"> 7. Incorporate evidence-based tools to assess transition readiness. 8. Take a comprehensive approach, incorporating multiple trajectories and where necessary working across organisational and sector boundaries. 9. Involve each young person in decision-making at every step, taking account of individual capacity, development, engagement style and advocacy needs. 10. Assess vulnerabilities and mitigate risks taking account of individual circumstances and conditions and associated management, care, and support requirements. 11. It is essential to facilitate peer support and learning opportunities throughout the transition process, including provision of specialist clinics and visits to adult service providers. 12. Take a whole family approach building a trusting reciprocal relationship by acknowledging experience and assets; acknowledge and resolve family fears and concerns. 13. Develop professional relationships which ensure young people's access to a network of appropriate resources which open-up new opportunities, community participation and promote self-advocacy. 14. Review the developing global evidence base regularly; contribute to a shared a learning culture which enables consistent best practice and service development. 15. Co-produce and evaluate service developments with young service-users. 	<p>Residential immersive life skills (RILS) programs for young people with disabilities. King, et al., (2021).</p> <p>The STEPS Curriculum - involving peer mentors for college students with autism spectrum disorder (Accardo, Kuder and Woodruff, 2019). (Hotez et al., (2018) highlight a similar successful participatory summer programme.)</p> <p>Spyridakou, Mendis and DeVal, (2019) - a replicable quality improvement project, engaging teenagers who have permanent hearing loss in transition preparation.</p> <p>Multidisciplinary/ Holistic Approaches</p> <p>Multidisciplinary Intervention Navigation Team (MINT) a hospital-wide Transition Programme for young adults with medical complexity including (Szalda et al.,2019)</p> <p>International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY) as a holistic framework (Hartman, McPherson, Maxwell, and Lindsay, 2018).</p> <p>Transferable use of a sociocultural framework to support the transition experiences of visually impaired school leavers (Williams, 2015).</p>
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3.5 Perceptions and Interconnected Experiences.

Current research and policy guidance is shaped by various viewpoints, depending on favoured research paradigms, traditions and established practice (Zhou et al, 2016; **Article 7** (Medforth and Boyle, 2022)). Examples include projects using randomised control design to seek evidence of improving outcomes (Harris, 2015; Hilderson et al., 2015; Peron et al., 2018, Toft, 2018; Camfield et al., 2019); development of scales to measure important transition-related bio-psychosocial constructs and psycho-social functioning (Klassen, et al., 2015; Santosh, et al., 2018; Hartman, McPherson, Maxwell, and Lindsay, 2018) and qualitative studies and intervention evaluations illuminating the experience and needs of young service users and families. In the case studies we reported in **Articles 3, 4, 5 and 6** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Medforth, Evans, Hills, Madden and Oyston, 2019; Medforth, 2022) we highlight the perceptions and interconnected experiences of young people, families, and practitioners.

Many of the best practice recommendations identified by young people, families and practitioners align with those highlighted by researchers; starting early and taking a holistic approach; prioritising identification of a lead professional to coordinate manage and document the transition process; ensuring integrated commissioning and services; having experienced transition practitioners who can help families to overcome some of the barriers and navigate hurdles; enabling the participation of young people in the co-production of services. Value is added by the complementary perspectives of representative service users, families, and practitioners, based on personal experience which led to transferable learning.

The need to incorporate a focus on healthy lifestyles, wellbeing and mental health, food, and nutrition in transition programmes, as well as how to navigate services was emphasised by young carers, young adult carers; young people in care and those with mental health difficulties (Broder et al, 2017; Sims-Schouten and Hayden, 2017; Jordan, Kane and Bibby, 2019; **Articles 3, 4, 5 and 6** Medforth and Huntingdon, 2018a; Medforth and Huntingdon 2018b; Medforth, Evans, Hills, Madden, and Oyston, 2019; **Article 6** Medforth, 2022; Lacey et al, 2022).

Young people recognised that benefits of facilitating peer support through young people's groups, special clinics, or interventions such as a young people's champions project are enhanced self-confidence and self-advocacy and enabling young people to feel less alone, unsure, anxious, unsafe **Articles 3, 4, 5 and 6** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon 2018b; Medforth, Evans, Hills, Madden, and Oyston, 2019; National Guideline Alliance (UK) (2021) ; Medforth, 2022; Richard et al, 2022; **Article 6** Medforth, 2022; Halsall, Daley, Hawke, Henderson and Matheson, 2022; de Beer, et al, 2024; Dave et al, 2024). Young people and families say they need reassurance that they will receive a service that is at least as effective in meeting their needs as the service that is familiar to them; young people in transition may still need parents there to explain and reassure, so parents should be informed of outcomes of assessments, development of plans, what is happening and completed actions (Waldboth et al., 2016; **Articles 3 and 4** Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Taylor, Cobigo and Ouellette-Kuntz, 2019; Waldboth et al, 2021).

Parents suggested that where young people are not able to confidently speak for themselves practitioners need enhanced communication skills to be able to advocate for the young person; training to enhance knowledge, skills and best practice in co-ordinating transition, with the possibility of parents being involved in training development **Articles 3 and 4** (Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b).

Specialist advocacy services would be particularly useful for young people with severe learning disabilities to ensure that the young person's wishes, concerns, goals, and feelings, developmental ability and communication style are accommodated, rather developing transition plans to fit existing models of service delivery (Okamura, Saunders and Rehm, 2015; Dunn, 2017; **Articles 3 and 4** Medforth and Huntingdon, 2018a; Medforth and Huntingdon, 2018b; Camfield et al., 2019; Scheef and Mahfouz, 2020; **Article 7** Medforth and Boyle, 2023). This may mean re-defining boundaries to negotiate service -user autonomy and alleviate the burden on young people and parents, as recognised in several countries including Belgium, Netherlands, Italy and England (Hendrickx, De Roek., Mara, and Dielman, 2020); China (Jiang et al., 2021); Canada (Gorter et al., 2015; Taylor, Cobigo and Ouellette-Kuntz, 2019;); Scotland (Reekie, 2020) and the USA (Sullivan, 2016). King et al.,

(2021) go further, raising the opportunity to open new life-course possibilities **Article 7** (Medforth and Boyle, 2022).

3.6 Service Development, Innovation, Evaluation, and Research.

Co-production (involving young people in the design, development and delivery of transition programmes) is essential, so participatory approaches which give young service-users and families stronger voices, and the transformative potential of action research are paramount (Hotez et al., 2018; Hughes, et al., 2018; Hagell, and Rigby, 2020; **Article 7** Medforth and Boyle, 2022). Equally important is ensuring that innovation and service development is underpinned by appropriate evidence and systematically evaluated. In **Article 7** (Medforth and Boyle, 2022) we found that current research approaches and priorities were varied; some were clinically focussed seeking quantifiable evidence for improving outcomes, for example, randomised control design projects to evaluate transition outcomes for specific groups, who are currently under-researched (Harris, 2015; Hilderson et al., 2016; Peron et al., 2018, Toft, 2018; Camfield et al., 2019; **Article 7** Medforth and Boyle, 2022).

Focus areas for future research are suggested; *assessing pathway effectiveness; developing guidance for strategic managers and practitioners and evaluating the role of parents.* (Rees, 2016; Waldboth et al., 2016; Allemang et al., 2019; Taylor, Cobigo and Ouellette-Kuntz, 2019). Systematic *longitudinal intervention studies and evaluations* should extend beyond 12 months post-transition, including those involving health related outcomes and preventative strategies for young people with complex disabilities and emergent mental health problems (Campbell et al., 2016; Salomon and Troller, 2018; Gorter et al., 2015, Colver et al., 2019). System level disintegration of the transition process across countries highlights the need for robust policy development and the use of powerful levers to elevate the profile of transition support development (Hepburn et al., 2015). A multi-dimensional perspective in the developing evidence base is essential; evaluating accessibility to under-represented groups and developing additional scales to measure important transition-related bio-psychosocial constructs and psycho-social functioning (Klassen, et al., 2015; Hartman, McPherson, Maxwell, and Lindsay, 2017; Santosh, et al., 2020; **Article 7** Medforth and Boyle, 2022).

In this chapter, I have identified that learning from research in my own peer-reviewed publications, when considered within the context of the wider evidence base indicates the need for on-going and wide- ranging research, innovation and service development. It also requires more comprehensive, integrative approaches at all levels if successful transition outcomes are to be achieved for all young people. In the next chapter I will conclude this thesis with an argument for re-thinking the concept of *transition* itself and the advancement of a bio- psycho- ecological approach to transition support which must be flexible, inclusive and tailored to meet needs of all young people.

Chapter 4: Re- conceptualisation, Conclusion and Recommendations.

4.1 The Case for Revisiting the Concept of Transition.

In previous chapters I have highlighted evolving approaches to research, innovation and development, and emerging moves towards integrated transition support services.

Alongside these developments, arguments advocating re-conceptualisation of the concept of *transition* itself have been advanced. Goals cited include:

- a) Need for a meta-theoretical understanding which includes the understanding of service users and research participants (Jindal – Snape, Symonds, Hannah, and Barlow, 2021).
- b) Interrogation of the underlying orthodoxy of biological maturation and age and acknowledgment of the social, cultural, political, and historical contexts that transform concepts of young person and adulthood in the 21st century (Wyn and Dwyer, 2002; Cuervo and Wyn, 2014; de Almeida Alves, 2023).
- c) Recognition of complexities associated with individual circumstances (Medforth and Huntingdon, 2018a; Medforth and Huntingdon 2018b; Medforth, Evans, Hills, Madden, and Oyston, 2019; Medforth, 2022; Medforth and Boyle, 2023).
- d) Challenging normative patterns of transition which have the effect of creating “*at-risk*” categories, inequalities, and marginalisation (Mizen, 2004; Kelly, 2006).
- e) A re-balance focusing on a range of educational and well-being outcomes to avoid a self-fulfilling negative discourse (Jindal – Snape, Symonds, Hannah, and Barlow, 2021).
- f) A focus on assets (Brooks and Kendall, 2013) to identify the protective factors that support learning, health, and wellbeing and resources that promote the self-esteem and coping abilities of individual young people.
- g) Holistic, biopsychosocial, and multi-agency approaches to transition support which respond to the young person’s style of engagement, concerns, and confidence level and incorporate attention to participation, the acquisition of skills and monitoring gains or losses, ability, and skill over time (Hartman, McPherson, Maxwell, and Lindsay, 2018; Colver et al., 2019).

- h) Evidence-based best practice in supporting successful transitions for young people must be aligned to developing national policy, priorities, and context; innovative approaches delivered in enabling environments that assure inclusivity, responsiveness and promote social cohesion (Education Development Trust, 2022).
- i) Local and global connectivity, learning outside of formal education to respond to a requirement on young people to become “*self-navigators*” (Woodman and Wynn, 2014) and enabling “*agency*” in young people with disabilities (Pearson, Watson, Gangneux, and Norberg, 2020).
- j) Greater recognition of the situations, culture, and relational aspects of young people’s lives, and the search for meaning and security in an unpredictable and unstable world; understanding that around the world young people undergo life-course transitions in societies which are undergoing deep transformation: dealing with the aftermath of the covid pandemic, confronting climate change and responding to increasingly accelerating technological change (Furlong and Cartmel, 1997; Furlong and Cartmel 2007; Education Development Trust, 2022).
- k) Specialist support for young people undergoing transitions related to gender identity (Proud Trust, 2024).

4.2 A proposed solution

Shah, Mathew, Pereira, Nakaima, and Sridharan, (2021) review and re-define the role of evaluation in iterative learning and implementation of quality care interventions. Their objective is to promote a shift from a summative focus toward an approach that promotes learning in complex systems. This shift includes a focus on concepts such as dignity and equity; person-centred care; rights-based approaches and taking a multi-disciplinary view. They recognise the role realist evaluation can play and the need to respond to complexity by considering interaction at various levels, taking a multi-dimensional view of quality care. They offer a framework which incorporates the following principles: being authentic to the service user journey; making respect and dignity matter; recognising that high quality care is anticipatory and systems wide. Their framework highlights the goal that intervention over time will lead to quality care provision if it acknowledges these principles as well as technical quality and best practice. Their framework and principles informed the development of my proposed solution, in combination with learning from across the range

of work referred to in this thesis. The ten iterative steps I undertook are summarised in **Appendix 3**.

My proposed solution may initially seem paradoxical: a return to the developmental theorists of the twentieth century and Uri Bronfenbrenner's *bio-ecological systems* approach (Bronfenbrenner, 1979; 2005). The value of applying this approach to complex transitions was recognised by Joly (2015) but not fully developed as an approach to support provision. Criticisms of Bronfenbrenner's approach include the difficulty in scientifically evaluating the theory and that it may be too deterministic (Leventhal & Brooks-Gunn, 2000). Tudge et al (2017) cautioned against misunderstanding and misapplying Bronfenbrenner's work, highlighting his revision and re-emphasis on the *interaction* between individual biological maturation and the external ecological context. Recent writers, however, have recognised the enduring value of application to the health and social care context.

Ornstein and Caruso (2024) recognise the value of the approach to the caregiving context across the life course; Paat (2013) highlights how it has been used to strengthen social work with immigrant children; Kelly and Coughlan (2019) used constructivist grounded theory analysis to apply the theoretical framework to youth mental health recovery. Harris and Holman-Jones (2023) report a creative adaptation used to support young people's mental health in schools and Hayes, O'Toole and Halpenny (2017) argue that is inclusive of all the systems children and their families experience.

Bronfenbrenner recognised that the individual child and young person develops in a multi-layered external environment, from immediate settings like family to broad cultural values and historical context. Bronfenbrenner's approach described five different systems which impacted on the child and adolescent summarised in Table 4.

Table 4: Core Concepts in Bronfenbrenner's Bio-Ecological Systems Approach.

Microsystem	The child's most immediate environment where there are bi-directional relationships, for example the child's most immediate relationships and environments. It could include parents, siblings, friends, school, and neighbourhood. Here Bronfenbrenner's ideas align with those of Vygotsky, where the immediate linguistic, social, cultural, generational and ecological worlds of the child enable them to extend their learning within their Zone of Proximal Development, shaped by the more experienced others they meet.
Mesosystem	The space where individual microsystems do not function independently but are interconnected and assert influence upon one another. For example, the interaction between a child's parents and school or health service can provide consistency across both environments whereas a problematic relationship with peers could lead to tensions within the family or offending within the community.
Exosystem	Involves other formal and informal social structures which do not directly interact with the child or young person but nevertheless still influences their microsystems. For example, concerns regarding family finances because of low wages could affect a parent's ability to recognise and respond to the needs of their child or cuts to mental health services may make them inaccessible, impacting on the wellbeing of the developing young person. Government policy, media and community resources will all begin to shape the development at this level.
Macrosystem	Is different from previous systems because it does not relate to immediate environmental factors, instead considering the cultural ideologies, attitudes, and social conditions that children are immersed in. It would be much easier, for example, for a young person who is struggling with gender identity to

	“come out” as transexual in a non-binary accepting, non-hostile or judgemental cultural environment or it may be very difficult for a disabled young person to thrive and achieve their aspirations when immersed in a society where ableist beliefs dominate.
Chronosystem	Introduces the concept of time. It acknowledges shifts and transitions over the child’s lifetime. Some environmental changes can be predicted, such as moving from primary to secondary school, whilst other stressors like family breakdown or bereavement may not. For Bronfenbrenner, as for Lev Vygotsky, historical events, significant political change, economic recession, cultural movements, advances in technology, war and peace can all interact with the other systems, impacting on the individual developing person. Shifting social expectations over the lifespan will all impact on the developing individual; the ways in which children respond to expected and unexpected life transitions depend upon the support of their ecological systems.

4.3 A Bio- psycho- ecological Approach to Transition

I have adapted these core concepts to develop a model that reconceptualises the concept of transition and locates it within the *bio-psycho ecological context* that shapes the young person’s experiences. Rather than directly applied, the concepts of *microsystem*, *mesosystem*, *exosystem*, *macrosystem* and *chronosystem*, are replaced with *Young Person at the Centre*; *Parent, Carer and Family*; *Locality and Community* and *Global Context*. This is because Bronfenbrenner made a distinction between *macrosystem* and *mesosystem* where there is a direct interaction with the world of the child and young person and the other systems where he suggested a more indirect effect. I have emphasised a more explicitly dynamic interaction between the young person and external context at every level, firstly because of the need to recognise the complexity and impact of the wider external context and secondly because of the potential for young people to become active self-navigators, impactful self and community advocates and politically or globally engaged citizens.

Figure 1: A Bio-Psycho Ecological Systems Approach to Supporting Young Peoples' Transition to Adulthood * Please see **Appendix 4** for fuller **explanatory notes** relating to the core concepts at each level.



Global Context

Generation, Geography and Global Events

Contemporary Political, Cultural and Economic Context

Transformation through Research, Technology, Policy, and Advancing Practice

Locality and Community

Community Assets and Diversity

Independence, Inclusion, Opportunities, Participation and Citizenship

Housing, Work, Recreation and Leisure

Parent, Carer and Family

Circumstances, Strengths, and Expertise

Social Network and Support to Navigate Services

Young Person at the Centre

Circumstances, Needs, Assets, and Abilities

Identity, Learning, Development, and Aspirations

Lifestyle, Friends, and Cultural Connection

Readiness for Transition, Support Needs and Outcomes

Health, Emotional Wellbeing and Safeguarding

Trust and Confidence in Services

Readiness to Let Go

Continuing Involvement

Legal Frameworks and Local Governance

Integrated Services

Co-production to Meet Needs of Communities Served

Innovative Service Development and Improvement

4.4 Application to Practice and Implications for Future Research

The approach provides an overarching contextual framework within which other more specifically focussed evidence-based pathways, assessment tools and models of service delivery and transition support could reside. It resolves the re-conceptualisation challenges highlighted previously, whilst enabling service providers to ensure that individual young people in complex circumstances experience holistic support and the best possible transition to young adulthood. A discussion paper disseminating this approach was published online in December 2024 **Article 8** for inclusion in the first journal edition of 2025 (Medforth, 2024).

Peer reviewers commented:

“An interesting and thought-provoking piece. Anecdotally In health care, the transition to adult services is certainly a grey area for CYP and families which is highlighted in your work...I find that you offer a reasoned argument on a complex subject, and, indeed, you have a novel perspective to offer.”

In summary, integrated approaches to *Transition* need to provide comprehensive support where it is needed to enable young people’s development across the full range of life-course trajectories. Organisational barriers will need to be overcome if the needs of young people are to be central to effective transition support. Integration of services (children and adult services; inter-professional training, working and learning and collaboration across traditional sector boundaries) will be essential and is likely to involve significant change in service-design, professional mind sets, organisational philosophies and ways of working. The BMJ (2010), for example, highlight how fifteen years ago Sir Ian Kennedy’s report on health services for children and young people recognised a required a re-focussing on the needs of young service users, rather than the needs of organisations, buildings, and professionals. Kennedy advocated that to better meet the needs of children and young people the money spent on children’s health from the NHS, social services, and education budgets should be pooled and administered under a new government department for children’s wellbeing. An integrated system of care is needed - this fundamental change is evidently still work in progress, particularly as it remains a barrier to comprehensive transition support as well as other aspects of health, wellbeing and opportunities to thrive and flourish.

Focus should reflect individual circumstances, responding to factors which make the journey to young adulthood complex. Priorities will reflect the concerns which are most important to young people and their families and what transition experiences mean to them, including along priority trajectories according to the young person's own developmental and social clock. Environment, culture, geographical and generational context may also impact. Support arrangements must recognise the strengths, assets, experiences, ideas, and aspirations of individual young people.

Transition Co-ordinators will be disability confident, trauma informed practitioners and play a key role in advocating for young service users, working with others across sectors and organisational boundaries. They will need to be confident in working inclusively with groups of young people of different ages from 11 upwards, who will be at varied stages of development and have different vulnerabilities, strengths, and abilities. This will be essential if they are able to effectively utilise the social capital and learning potential that facilitating peer support brings throughout the transition process. Facilitating peer support could include workshops, peer support groups, transition champion programmes, specialist clinics, and visits to adult service providers. To be effective this may require collaboration between lead professional practitioners who can share complimentary skills and expertise, for example health practitioners, youth workers, teachers and social workers. Imaginative innovations could also involve art therapists, community musicians, theatre groups and third sector partners.

Whilst existing tools, models and integrated pathways are useful it will be necessary to organise relevant services into multi-agency hubs or co-ordinate them into representative teams. Regular collaboration can lead to development of services that fully meet the needs of individual young people and innovatively respond to complex circumstances and challenges. Involvement must include representatives from both young peoples' and adult services to establish shared goals and understanding. Innovation and service development will be informed by the global research evidence base and local, national, and international policy context. Most importantly young service user voices should shape service development. Learning should be widely disseminated to achieve demonstrable impact.

To conclude, by drawing on the range of my peer -reviewed publications this thesis has critically examined the concept of transition from the perspectives of both its

developmental origins, and application to range of professional, research and sector-specific service provision contexts. Primary research, user-focussed service evaluation and integrative evidence synthesis has illuminated a myriad of challenges and foci for best practice in providing effective young person-centred support services. Analysis led to recognition of problematic aspects of linear and disciplinary or sector-centric approaches and scope for significant service improvement; evaluation of delivery, service user experience and demonstrable positive outcomes, are key, particularly for those young people whose circumstances are complex.

4.4 Conclusion and Recommendations

Comprehensive and holistic approaches to transition continue to evolve, integrating learning from global research, advancing practice, service development and innovation projects. The need for fundamental change is evident. I have responded to calls for a re-conceptualisation of *transition* itself, proposing a new comprehensive bio-psycho-ecological model, within which evolving evidence-based, practice tools and innovations can reside. Ensuring the voice of young service users is central to meeting the significant and globally recognised challenges. Through collaboration between disciplines and across sectors the rewards and outcomes can be greater. We have the potential to not only empower young people to become self-advocates, and confident service-navigators but also enable them to become active citizens, living the fullest lives possible, however complex their individual circumstances. In summary I offer the following recommendations to work towards achieving this:

1. Researchers should continue to contribute to the evolving evidence base, including collaboration across regional and national boundaries. Foci must include aspects of transition previously identified as priorities, such as the experience of marginalised groups of young people, the contribution of parents and carers, assessing pathway effectiveness and longitudinal evaluation of clinical and wellbeing outcomes and life chances over the life course. A multi-dimensional perspective in the developing evidence base is essential, evaluating accessibility to under-represented groups and developing additional scales to measure important transition-related bio-psychosocial constructs and psycho-social functioning.

2. Young service users and their families should be actively encouraged to contribute to the co-production of research projects and the evaluation, development and continuing improvement of services. They could also contribute towards providing transition training to practitioners and service leads.
3. Policy makers, commissioners and service leaders should consider developments in light of the evolving global evidence base, paying particular attention to the voice of young service users. Policy makers must acknowledge the need for robust policy development and use powerful levers to elevate the profile of transition support development.
4. Policy makers, commissioners and service leaders will take a more holistic and comprehensive approach; aligning research, delivery models, pathways and assessment tools to the comprehensive bio-psycho-ecological systems approach proposed. (See Appendix 2 for explanatory notes.)
5. Service re-design will include provision for the physical co-location of services or other mechanisms to facilitate essential cooperation between children's and adult services and inter-professional, multi-agency collaboration.
6. Service providers and commissioners will ensure that transition programme development and implementation is guided by young people's assets, aspirations, and preferences. This includes the promotion of health literacy and wellbeing and how to navigate services.
7. Commissioners will ensure strategic support underpins service commissioning and systematically monitor and evaluate outcomes, ideally longitudinally.
8. Service providers must actively facilitate advocacy where required and provide transition training for young people, families, practitioners, and service-providers.
9. Service leaders must identify a suitably trained and skilled Transition Co-ordinator and successor in case of staff turnover.
10. Service providers and Transition Co-ordinators will start the planning process as early as possible (ideally around 12 years of age) acknowledging that it may take up to 7 years. Service providers and Transition Co-ordinators will incorporate evidence-based tools to assess transition readiness.

11. Service providers and Transition Co-ordinators must ensure a documented Transition Plan is in place using established models, tools, passports, and technology where appropriate. This will be reviewed annually in partnership with all stakeholders.
12. There will be many young people in complex circumstances requiring transition support in each locality so planning and review should include both individual plans and sustained peer support mechanisms throughout the process.
13. Service providers and Transition Co-ordinators will take a comprehensive approach, and where necessary work across organisational and sector boundaries to bring together services which can respond to holistically to the individual needs of young people. The contribution of local community and voluntary sector agencies and young people's services should not be overlooked.
14. Service providers and Transition Co-ordinators will involve each young person in decision-making at every step of their own transition, taking account of individual capacity, development, engagement style and advocacy needs.
15. Service providers and Transition Co-ordinators will ensure that essential peer support and learning opportunities throughout the transition process are assured, including provision of specialist clinics and visits to adult service providers.
16. Service providers and Transition Co-ordinators will take a whole family approach building a trusting reciprocal relationship by acknowledging experience and assets; acknowledge and resolve family fears and concerns.
17. Service providers and Transition Co-ordinators will develop professional relationships which ensure young people's access to a network of appropriate resources which open-up new opportunities, community participation and promote self-advocacy.
18. Service providers and Transition Co-ordinators will assess vulnerabilities and mitigate risks, taking account of individual circumstances and conditions and associated management, care, and support requirements. Any post-transition dis-engagement or loss to adult services should be routinely followed up.

19. Researchers, policy makers, commissioners, service leaders, service providers and Transition Co-ordinators will review the developing global evidence base regularly; contribute to a shared a learning culture which enables consistent best practice and service development.
20. Researchers, policy makers, commissioners, service leaders, service providers and Transition Co-ordinators will co-produce and evaluate on-going service developments in partnership with young service-users to ensure they have an active role in continuing improvement. Quality assurance tools developed for young people's services such as *You're Welcome* (H.M. Government, 2023) should be used as benchmarks.

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Part 2: Selected Peer-reviewed Publications

2.1 Early Development of Children's Health Literacy and Self-Advocacy

The importance of enabling all children and young people to develop self-advocacy skills is widely recognised, particularly for children with disabilities. It has been incorporated as a key aspect of transition planning. For young children who are potential users of health and care services a developing understanding of service systems and how to navigate them, as well as giving feedback on experience as a service-user is an essential foundation for developing self-advocacy and health literacy. Articles 1 and 2 evaluate innovations which demonstrate ways in which young children can be enabled to begin to develop knowledge and skills which will be useful tools at later life stages. The evaluations contributed to the case for provision of health, well-being and N.H.S. focussed resources to primary schools throughout England and the wider roll-out and implementation of the Children and Young People Friendly version of the Friends and Family Test in the NHS.

Article 1.

Nicholas Medforth, Hannah Timpson, Daz Greenop & Rachel Lavin (2015) Monkey's health service: an evaluation of the implementation of resources designed to support the learning of primary school-aged children in England about healthy lifestyles and NHS services *Issues in Comprehensive Pediatric Nursing*, 38:3, 181-201, DOI: 10.3109/01460862.2015.1049385 <https://www.tandfonline.com/doi/abs/10.3109/01460862.2015.1049385>

Abstract

The National Health Service Institute for Innovation and Improvement was established to help the NHS to improve healthcare by rapidly developing and disseminating knowledge and evidence about new ways of working. One example is the Emergency and Urgent Care Pathway for Children and Young People which focused on providing high quality and safe healthcare for children and young people requiring urgent or emergency treatment for the most common illnesses and injuries. Monkey's Guide to Healthy Living and NHS Services was developed to increase awareness of acute health services in primary school-aged children. This free resource was posted to every primary school in England. A process and impact evaluation were undertaken to explore how the resource was being utilized during 2013–2014. A small number of in-depth case studies were developed involving classroom-based

observations and teacher interviews along with a much larger online survey which was emailed to all primary schools in England. Overall, the resource was viewed as useful, engaging, and informative; with children, teachers, and other professionals particularly valuing the monkey puppet, video clips, and teacher resources. The National Evaluation highlighted that most respondents integrated the materials into the curriculum, used them as a one-off lesson, or developed their own innovative and strategic approaches to make the best use of the resources; almost two-thirds of schools who responded to the survey felt the resources led to pupils knowing about the available NHS services and healthy lifestyles; over half felt pupils were now more informed about the most appropriate services to use.

<https://www.tandfonline.com/doi/abs/10.3109/01460862.2015.1049385>

Article 2.

Medforth N, Rooksby K. (2017) Enabling Young Service Users to Provide Feedback on their Experience: An Evaluation of the Pilot Implementation of Children and Young People Accessible Friends and Family Test in General and Dental Practices in NHS England South (South Central). *Comprehensive Child and Adolescent Nursing* 2018 Mar;41(1):42-57. doi:10.1080/24694193.2017.1316789. Epub 2017 May 1.

<https://www.tandfonline.com/doi/pdf/10.1080/24694193.2017.1316789>

Abstract

Involvement of service users in the delivery and development of services by providing unique feedback on their own experiences is a well-established feature of continuing improvement and quality enhancement. The Friends and Family Test (FFT) is a tool that supports the fundamental principle that people who use NHS services should have the opportunity to provide feedback on their experience; however, children and young people are a group of key stakeholders whose voice has not been routinely sought. This article summarises the evaluation of a pilot project which aimed to implement and test the utility of a children and young people friendly version of the FFT in general and dental practices with a view to making it more widely available in the future. One exemplar Case Study is provided, and findings lead to recommendations on how to ensure the FFT is continually made accessible to children and young people.

<https://www.tandfonline.com/doi/pdf/10.1080/24694193.2017.1316789>

2.2 Experiencing Complexity – triangulated case studies of young people lost and found in complex health transitions.

The two articles below draw on a report commissioned by a Clinical Strategic Network in the north of England who were aware of the challenges in getting transition planning and support right for young people with complex health needs and disabilities. The aim was to identify areas for service development by gaining deeper insight into the recent transition experiences of young people and families and the professionals involved. Triangulated Case Studies illuminate the experiences of young service-users, their families and professionals involved in planning and providing support during the transition process. Learning from the project led to recognition that there were still significant gaps in integrated service provision. New service-providing networks were developed to explore how strategic improvements could be made.

Article 3.

Nicholas Medforth & Elaine Huntingdon (2018) Still Lost in Transition? *Comprehensive Child and Adolescent Nursing*, 41:2, 128-142, DOI: 10.1080/24694193.2017.1330370

Abstract

Numerous policy directives highlight the need for planned and well-coordinated support to enable young people with long-term conditions and disabilities to negotiate the transition to adulthood, including making the leap from children-oriented to adult-centred health services. The journey is complex and multi-dimensional. For young people with a disability, long-term condition, or mental health problem there are additional challenges when transitioning between services with differences in expectations, delivery, and culture. This article explores findings from 6 case studies of young people who have recently experienced transition to adult health and care services, triangulating inter-related perspectives: those of young people, parents, and carers, and where possible the professionals involved. One of the case studies illustrates how the challenges are experienced. Analysis of emerging themes across the case studies leads to key messages from families to inform strategic development of services and practice.

<https://www.tandfonline.com/doi/full/10.1080/24694193.2017.1330370>

Article 4.

Nicholas Medforth & Elaine Huntingdon (2018) Found in Transition, *Comprehensive Child and Adolescent Nursing*, 41:4, 237254, DOI: 10.1080/24694193.2017.1323976

Abstract

The journey to adulthood is complex and multi-dimensional. Young people may be independent in some spheres of their lives, but dependent in others. For young people with a disability, long-term condition, or mental health problem there are additional hurdles. As they move between health and social care services, they will find significant differences in expectations, delivery, and culture. At the same time, their own needs will be evolving. Despite a great deal of guidance on effective transition support, in 2014, England's Care Quality Commission highlighted a shortfall between policy and practice. The result is confusion and frustration for young people, their families, and the staff caring for them. Seamless transition to adult services is by no means a universal experience. Here the authors offer two case studies that triangulate inter-related perspectives: those of young people, parents and carers, and the professionals involved in successful models of transition support. The case studies illustrate how the challenge of transitioning to adult services is experienced and how, despite some concerns held by young people, parents, and carers, well-planned and coordinated transitions can have positive outcomes for the families involved. <https://www.tandfonline.com/doi/pdf/10.1080/24694193.2017.1323976>

2.3 Overcoming Adversity During Transition: case study-based evaluation of projects aiming to support healthy lifestyles, self-care, self, and community advocacy.

Self-care and the development of healthy lifestyle choices are important aspects of the transition towards young adulthood. These may not always have been the priority for young people growing up in adverse circumstances. The two articles below explore this alongside other aspects of the journey. The first article was based on a commissioned evaluation of a local project designed to promoting healthy eating and lifestyles in looked after young people. Triangulated case studies drew on the experiences shared by young people and their foster carers and the lead practitioner's learning. The report was used to inform future commissioning decisions.

Article. 5.

Medforth, N, Evans, J, Hills, M, Madden, H and Oyston, J (2019) *Hearty Lives (Liverpool): a case study-based evaluation of a project designed to promote healthy eating and lifestyles in looked after young people*. Adoption and Fostering, 43 (1). ISSN 0308-5759

<https://www.semanticscholar.org/Article/Hearty-Lives-%28Liverpool%29%3A-a-case-study-based-of-a-Medforth-Evans/95a2de660415df27b7e2462c1ceb9d123625817a>

Abstract

Unhealthy weight and lifestyle are specific issues for young people who are in the care of their local authorities under the supervision of social services. There is a close relationship between food, nutrition and family connectedness. Following the principles of Appreciative Inquiry, this small - scale evaluation of the Hearty Lives (Liverpool) project, uses a case study approach to gain insight into the learning and experiences of those involved in interventions to promote healthy eating and lifestyles in looked after young people. Learning gained provides useful insights to practitioners and organisations who are interested in developing similar projects or interventions

<https://journals.sagepub.com/doi/10.1177/0308575918823432>

The second article was based on a commissioned evaluation of a national Young Carer Health Champions programme which brought together young carers and young adult carers from across England, establishing a network of peer support, facilitating sharing of experiences, and improving confidence, health literacy and wellbeing. The evaluation involved the experiences of a cohort of young people who actively participated in the programme as well as case studies illuminating how individual young people had become champions for young carers and young adult carers nationally and within their own regions. The evaluation was used to inform ongoing development and commissioning of the programme.

Article 6.

Medforth, N. (2022) *"Our Unified Voice to Implement Change and Advance the View of Young Carers and Young Adult Carers."* An Appreciative Evaluation of the Impact of a National Young Carer Health Champions Programme. Social Work in Public Health, DOI: 10.1080/19371918.2022.2058673

Abstract

Growing evidence highlights the challenges and support needs of young carers and young adult carers, however research and policy frequently neglect the voice and experience of young people themselves. A team at NHS England developed the Young Carer Health Champions programme to bring together young carers and young adult carers from across England, establishing a network of peer support, sharing of experiences and improving confidence, health literacy and wellbeing. This commissioned independent evaluation aimed to explore the impact of the programme and inform future delivery. Taking a qualitative case study approach, young participants have a central voice, illuminated through the observations of the researcher during residential activities, and data generated during a focus group and telephone and on-line interviews. Findings demonstrate positive impact on the personal development and lifestyles of the Young Carer Health Champions, and their journey from beneficiary to pro-active shaper of services and policy.

<https://www.tandfonline.com/doi/full/10.1080/19371918.2022.2058673#abstract>

2.4 Reviewing the Developing Global Evidence Base and Contribution to the Developing Discipline.

The review below synthesises the growing global evidence base evaluating the effectiveness of transition programmes, interventions, tools, and pathways. It was accepted for publication in August 2023 in a Special Edition of the Taylor and Francis journal *Comprehensive Children and Young People's Nursing*. This Special Edition focuses on current research and practice in Transition support. I was invited by the Editor to submit a commentary which was also been accepted for the same issue.

Article 7.

Medforth, N., & Boyle, C. (2023). Challenges, Complexity, and Developments in Transition Services for Young People with Disabilities, Mental Health, and Long-Term Conditions: An Integrative Review. *Comprehensive Child and Adolescent Nursing*, 46(3), 180–200.

<https://doi.org/10.1080/24694193.2023.2245473>

Abstract

Transition to adulthood for young people is complex and multi-faceted, with additional hurdles for young people who have disabilities, long-term, or life-limiting conditions or

mental health problems. The challenges in providing effective transition support are not new; researchers, policymakers, commissioners, and service providers have been grappling with the problem for several decades, with varying degrees of success. The aims of this integrative review were firstly to build on previous research to synthesize and evaluate recently published evidence. Secondly to provide an overview of the effectiveness of interventions (in one or a combination of health, social care, and education transitions) designed to support transition to adulthood in these groups of young people. A search of a range of databases retrieved published literature from January 2015 to January 2021 demonstrating global interest in the topic. Fifty-one articles were included following an appraisal of quality and eligibility. Qualitative, quantitative, mixed methods studies, and evidence synthesis were included. Some studies were clinically orientated whilst others examined the impact of the transition process or utilized participatory approaches which give young service-users and families a voice. Transition between children's and adult health or care services as well as other life-course trajectories, such as life-skills development, education transitions, social inclusion and employability were evaluated. Thematic analysis and synthesis of articles retrieved in this review highlighted themes identified in previous reviews: timing of, and preparation for transition; perceptions and experience of transition; barriers and facilitators; transition outcomes. Additional themes included special considerations; dealing with complexity; advocacy, participation, autonomy, aspirations, and young people's rights; future work, research, and evaluation. Novel perspectives and diverse data sources contributed to holistic understanding of an ongoing priority for international policy, service development, and research: the complexity of providing effective transition support and achieving positive outcomes for young people with long-term and life-limiting health conditions, disabilities, and mental health difficulties.

<https://www.tandfonline.com/doi/pdf/10.1080/24694193.2023.2245473>

2.5 Towards a new approach

This article synthesises learning from the previous papers and concludes the learning journey, with a recommended reconceptualisation of the concept of transition and its application to approaches to providing support to young people whose journeys to adulthood are complex.

Article 8.

Medforth, N. (2024). Do We Need to Re-Think *Transition* to Take a More Comprehensive Approach to Supporting Young People to Navigate Complex Journeys to Adulthood? *Comprehensive Child and Adolescent Nursing*, 1, 25).

<https://doi.org/10.1080/24694193.2024.2437704>

Abstract

This discussion paper draws on a range of personal and other published research articles to respond to calls for a re-conceptualization of the concept of *Transition*. Acknowledging the roots of the concept in developmental and health psychology, the article briefly considers application to fields of practice in formal and informal education, health, social care, counselling, and psychotherapy that underpin approaches to supporting young people to navigate the journey to adulthood. UK service provision is discussed to consider why linear developmental approaches may be problematic, alongside recent calls for a re-conceptualization of what we mean by *Transition* to successfully understand, support, and enable complex journeys to young adulthood. The paper concludes by proposing a holistic, non-linear bio-ecological systems approach within which it is possible to integrate globally evolving research, pathways, models, and interventions. The approach will be of interest to an international readership because principles can be adapted to respond to shared and country-specific challenges, developments, and models of service provision as we approach the second quarter of the twenty-first century.

<https://doi.org/10.1080/24694193.2024.2437704>

2.6 Contributing to the learning and understanding of educators and future practitioners and service providers.

Supporting Journal Special Edition with Commentary

I was invited to provide the brief commentary below for inclusion in a special edition of the Taylor and Francis journal *Comprehensive Child and Adolescent Nursing* focussing on Transition support: Medforth, N. (2023). Young People Lost and Found in Transition? *Comprehensive Child and Adolescent Nursing*, 46(3), 177–179.

<https://doi.org/10.1080/24694193.2023.2201317>

Supporting Book Chapter

The chapter below has been included in an internationally established textbook aimed at students of Children and Young People's Nursing. The book is in its 3rd Edition and has become a core text for students, underpinning the development of their professional knowledge. Learning from my ongoing research enabled the development of illustrative case studies and exercises suggested as activities within the chapter.

Medforth N. Chapter 29. Transition to Young Adulthood – A Particular Challenge for Developing Young People with Long-Term or Life-Limiting Conditions and Disabilities in Glasper, A., Richardson, J. and Randall, D. (2019) *A Textbook of Children's and Young People's Nursing* (3rd Edition). London. Elsevir. ISBN:97807020262322 (pbk) Available at LJMU Avril Robarts Library. Main Collection; 618.920023. GLA

Appendices

Appendix 1: Summary of Code and Theme Mapping identified across Peer-Reviewed Publications and used in Findings Section of the Thesis

Cross-Cutting Themes	Laying the foundations of self-care, self-determination and citizenship through advocacy and innovation.	Young people transitioning to young adulthood in challenging circumstances; shared challenges and additional complexities.	Preparation and readiness for transition; gaps, barriers and facilitating factors.	Outcomes post transition and recommended service development, innovation and research	Perspectives and interconnected experiences.
	Codes: Healthy Lifestyle Health Literacy (HL) Health and Wellbeing (HWB) Nutrition (N) Learning about and navigating Services (LNS) Advocacy (A) Independence and Self-Care (SC) Participation and Citizenship (PC)	Codes: Transition in challenging circumstances (TCC) Dealing with complexity (DC) Multiple Trajectories (MT)	Codes: Preparation (P) Coordinator Role (CR) Readiness (R) Gaps (G) Barriers (B) Facilitators and Best Practice (FBP) Tools and Pathways (TP)	Codes: Fear and Uncertainty (FU) Exclusion (E) Inclusion (I) Loss to follow-up/ poor clinical outcomes (LFUPCO) Compromised mental health and wellbeing (CMHWP) Positive Outcomes (PO)	Codes: Interconnected Experiences (PIE) Lost or Found in the transition experience (LFT) Young Person Person's Perspective (YPP) Family/ Carer Perspective (FCP) Professional / Practitioner Perspective (PPP) Research / Policy Perspective (RPP) Best Practice Recommendations (BPR)
Article 1 Medforth, N, Timpson, H., Greenop, D and Lavin, R. (2015) Monkey's health service: an evaluation of the implementation of resources designed to support the learning of primary school-aged children in England about healthy lifestyles and NHS services.	Theme evident ✓ Codes found on one or more occasion:				Theme evident ✓ Codes found on one or more occasion:
Article 2 Medforth N, Rooksby K. (2017) Enabling Young Service Users to Provide Feedback on their Experience: An Evaluation of the Pilot Implementation of Children and Young People Accessible Friends and Family Test in General and Dental Practices in NHS England South (South Central).	Theme evident ✓ Codes found on one or more occasion:				Theme evident ✓ Codes found on one or more occasion:

Article 3 Medforth, N. and Huntingdon, E. (2018) Still Lost in Transition?	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:
Article 4 Medforth, N. & Elaine Huntingdon, E. (2018) Found in Transition.	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:
Article 5 Medforth, N, Evans, J, Hills, M, Madden, H and Oyston, J (2019) Hearty Lives (Liverpool): a case study-based evaluation of a project designed to promote healthy eating and lifestyles in looked after young people.	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:
Article 6 Medforth, N. (2022) "Our Unified Voice to Implement Change and Advance the View of Young Carers and Young Adult Carers." An Appreciative Evaluation of the Impact of a National Young Carer Health Champions Programme.	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:
Article 7 Medforth, N., & Boyle, C. (2023). Challenges, Complexity, and Developments in Transition Services for Young People with Disabilities, Mental Health, and Long-Term Conditions: An Integrative Review.	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:	Theme evident ✓ Codes found on one or more occasion:

Appendix 2: Explanatory notes to accompany diagram of the Bio-Psycho-Ecological approach to Transition Support

Young Person at the Centre

The diagrammatic representation places the developing young person at the centre. The approach takes account of cognitive, social, and emotional development; the young person's developing sense of identity, sexuality, culture and understanding of how they are "known" to and relate to other people. This includes family, evolving relationships, peer support and friendships.

The individual needs and circumstances of the young person, including complex challenges, personal strengths, and assets are acknowledged and the individual young person's aspirations, continuing education, and employment goals are key. Health and lifestyle, disabilities and specific long-term conditions, emotional wellbeing and safeguarding are essential considerations. The young person's developing self-advocacy and communication skills are acknowledged. Decisions can be made regarding professional, or multi-agency support needed to be able to access and navigate transition between services. Here the young person's current experience and trust in services will be significant and will shape what transition will mean to them, their preparation and readiness for their own transition to young adulthood and how they evaluate their experiences. Housing may be another important consideration as the young person progresses to increasing financial independence and self-determination.

Young people will be central to service developments and provision as they transition to young adulthood. Providers will support young people in their preparation and readiness for transition, with an identified Transition Co-ordinator bringing together relevant stakeholders and service providers to ensure a comprehensive approach. Transition Co-ordinators will be skilled advancing practitioners, with effective communication skills and the ability to engage and work responsively in partnership with all young people and their families, including those living with specific challenges and complexities. Transition co-ordinators will be confident in developing a relationship of trust with young people and their families and be able to effectively assess the needs of young people, their language and communication needs, cognitive, behavioural, social, and cultural development. They will evaluate young people's level of trust and confidence in current and future services, helping young people and families to navigate systems. Where there are unmet needs they will work across boundaries, between sectors and with children's and adult services to ensure adequate service provision. Key considerations will include:

- Health, lifestyle, strengths, assets, and disabilities.
- Specific individual challenges and circumstances.
- Mental Health, wellbeing, and safeguarding.
- Identity and sexuality.
- Independence and self-determination.
- Attachments, relationships, friendships, and peer support.
- Communication ability and preferences, digital connectivity, and culture.
- Aspirations, continuing education, employability, and leisure.
- Advocacy, participation, and citizenship.
- Young person's own social clock and developmental pace.

Parent, Carer and Family Experience

The young person's family or carers may be pivotal in the young person's transition experience, not least because they are likely to know the young person best and be key sources of support to young people when accessing and navigating a range of services. Experts through experience, they will play a part in shaping the young person's transition. Family circumstances may bring complexities requiring additional support as well as assets and resilience which can be drawn upon to support the young person. Parents, carers, and siblings may also be impacted by the process themselves and face their own challenges such as loss of services or trusting in letting go as the young person becomes increasingly independent.

Service providers and policy – makers will need to recognise family experience, coping and expertise and acknowledge the feelings, concerns, and hopes of the young person's family. Working in partnership involves recognition that trust will need to be built not only with the young person but also achieve the confidence of parents and carers. Insights of siblings and the possible impact upon them should be considered. Depending on their developing level of independence the young person who is transitioning may value the continuing involvement of parents and carers. Families who have been used to advocating for the young person or fighting for services may need support to navigate available services, identify gaps or be able to assist in the peer support of other families. Where young people have caring responsibilities or are growing up in the care of the local authority support will require specific multi-agency transition planning.

Locality and Community

Assets and resources in the young person's local community will be essential to supporting the best possible transition outcomes. Integrated approaches to commissioning will ideally support the development of training, service providing hubs, models, and pathways. These should respond to the diverse needs of the community served, including young people living with complexity. Continuing education, health (including mental and sexual health), social care, youth, leisure, and housing services will need to be willing to work collaboratively, in new ways, across traditional boundaries. The contribution of community, faith, voluntary and independent sector services should not be overlooked. Collaboration with employers will be essential in creating opportunities for young people, including pathways to employability and supported internships; disability confident employers will be assets, creating working environments and practices that value neuro (and other diversities) bring to the workplace.

Specialist organisations who have expertise in particularly complex circumstances of individual young people may make an invaluable contribution; the youth justice sector is one example who will play a key role when a young person's behaviour is challenging, or they have problematic relationships with statutory organisations.

Counselling, advocacy, and participation services may also be useful to the young person alongside groups and services that facilitate peer support, help young people to overcome social isolation and promote citizenship. Opportunities for continuing learning and career development will also be key, with specialist support provided for young people who face challenges such as learning disabilities, neurodivergence or mental health challenges. Employability support services may need to be creatively tailored to meet the specific needs of young people, for example those who are furthest from education or employability because of social exclusion, disability, mental health, or family circumstances. Local knowledge and public consultation will enable service development to respond to the needs of the communities served. Groups within the community who may currently be underserved should also be enabled to drive innovation.

For young people, whose circumstances are complex there will be a need to provide holistic solutions (in both young peoples and adult services), modelled to ensure the needs of the young person are at the centre. Development of services should involve co-production with young service users and enable young people to give feedback on their experiences, so they play a significant role in quality assurance and improvement. Some may wish to represent or champion service development for less confident or more vulnerable young people in circumstances like their own. Youth and community and advocacy services may provide expertise or innovative approaches to support young people to become self or community advocates. Experienced parents and carers may wish to provide peer support or transition training for others new facing their child's transition

Global Context

The approach recognises that consecutive generations of young people are developing at a specific point in historical time and geographical location. They will share some aspects with previous generations but also experience an external environment unique to them. Global influences, may, for example include developments in the digital environment, technological advances, and changes in work patterns. Other impacting factors include global events such as the covid pandemic, armed conflicts, or climate events, all potentially impacting on mental health and wellbeing. Dominant cultural ideologies, attitudes, and social conditions that children are immersed in may be considered.

Innovation in transition support and service development will reflect the contemporary political, economic and cultural environment, informed by the developing research evidence base. Policy and guidance must be achieved through collaboration at local, regional, national, and international levels. Evidence based tools, models, pathways, and outcome measures will support service providers to advance practice.

Inclusion of the voice of young people will become routine in both the development and evaluation of services at local, regional, and national level with young people making an active contribution to national and international culture and politics. The rights of young people should always be upheld according to the United Nations Convention on the Rights of the Child (1989) and the European Convention on Human Rights (1950) whilst progress towards equality and global social justice will be made through the incremental achievement of the United Nations Sustainable Development Goals (2015). Young people can develop political agency through participation in school councils, youth parliaments, student unions and political parties. Social media provide possibilities for global connectivity and developing social movements unimagined by previous generations.

Appendix 3: Outline summary of the iterative process I underwent to developing the Bio-Psycho Ecological Systems Approach to Supporting Young Peoples' Transition to Adulthood

1. **Reflect** on learning from across the work contributing to the thesis, including empirical work, evidence synthesis, and identified cross-cutting themes.
2. **Synthesise** arguments for re-conceptualisation of transition; work towards including a more comprehensive non-linear approach that can be applied flexibly yet still include established or evolving models, pathways programmes and tools.
3. **Incorporate** the objective of shifting towards promoting learning in complex systems to improve quality of service provision, including consideration of service user journey; the continuum of care over time; technical quality and best practice and multi-agency collaboration.
4. **Reflect** on how the approach can include a focus on assets; protective factors that support learning; health and wellbeing and resources that promote the self-esteem and coping abilities of individual young people.
5. **Consider** how the approach will facilitate response to the young person's style of engagement, concerns, and confidence level. Pay attention to participation; the acquisition of skills and monitoring gains or losses, ability, and skill over time; local and global connectivity. Include learning outside of formal education to respond to the requirement for young people to become *self-navigators* and develop *agency*.
6. **Consider** how evidence-based best practice in supporting successful transitions for young people must be aligned to developing national policy, priorities, and global research context.
7. **Reflect** on how the emerging approach has scope to incorporate innovative approaches delivered in enabling environments that assure inclusivity, responsiveness and co-production.

8. **Revisit** Bronfenbrenner's Bio-Psycho Ecological Systems approach and consider how it might apply to the situations, culture, and relational aspects of young people's lives; their search for meaning and identity and life-course transitions in societies which are undergoing deep transformation. Acknowledge geographical and generational impact.
9. **Translate** to an approach to supporting young peoples' transition to adulthood that is expressed in simple summary terms which are more accessible to service users and providers, service commissioners and policymakers. Provide explanatory notes.
10. **Consider** how young service users might transcend the systems bi-directionally as they develop from recipients of services to self and community advocates.

Appendix 4: Confirmation of Lead Authorship

Re: Nicholas Medforth, Hannah Timpson, Daz Greenop & Rachel Lavin (2015) Monkey's health service: an evaluation of the implementation of resources designed to support the learning of primary school-aged children in England about healthy lifestyles and NHS services Issues in Comprehensive Pediatric Nursing, 38:3, 181-201, DOI: 10.3109/01460862.2015.1049385

I confirm that Nick Medforth was the lead author on this publication and contributed at least 70% to the development, writing and submission of the publication. This included

- acquisition of the commissioned project
- substantial contribution to conception and design, acquisition analysis and interpretation of data
- drafting and revising the article for peer review
- final approval of the version to be published.

Yours Faithfully



Dear Nick,

I am emailing to confirm that Nick Medforth was the lead author on the below publication and contributed at least 70% to the development, writing and submission of the publication. This included

- acquisition of the commissioned project
- substantial contribution to conception and design, acquisition analysis and interpretation of data
- drafting and revising the article for peer review
- final approval of the version to be published

Nicholas Medforth, Hannah Timpson, Daz Greenop & Rachel Lavin (2015) **Monkey's health service: an evaluation of the implementation of resources designed to support the learning of primary school-aged children in England about healthy lifestyles and NHS services** *Issues in Comprehensive Pediatric Nursing*, 38:3, 181-201, DOI: [10.3109/01460862.2015.1049385](https://doi.org/10.3109/01460862.2015.1049385)

Thank you,

Hannah

Dr Hannah Timpson

Reader in Socioeconomic Engagement in Health

Head of Research Engagement and Impact

Public Health Institute

World Health Organization Collaborating Centre for Violence Prevention

See Violence Info for global evidence on all forms of interpersonal violence:
<http://apps.who.int/violence-info/>

RE: Article - **Medforth, N, Evans, J, Hills, M, Madden, H and Oyston, J (2019) Hearty Lives (Liverpool): a case study-based evaluation of a project designed to promote healthy eating and lifestyles in looked after young people. *Adoption and Fostering*, 43 (1). ISSN 0308-5759 ***

To whom it may concern:

I confirm that Nick Medforth was the lead author on this publication and contributed at least 70% to the development, writing and submission of the publication. This included

- acquisition of the commissioned project
- substantial contribution to conception and design, acquisition analysis and interpretation of data
- drafting and revising the article for peer review

- final approval of the version to be published.

Best wishes,

Mel

RE: Article - **Medforth, N, Evans, J, Hills, M, Madden, H and Oyston, J (2019) Hearty Lives (Liverpool): a case study-based evaluation of a project designed to promote healthy eating and lifestyles in looked after young people. Adoption and Fostering, 43 (1). ISSN 0308-5759 ***

I confirm that Nick Medforth was the lead author on this publication and contributed at least 70% to the development, writing and submission of the publication. This included:

- acquisition of the commissioned project
- substantial contribution to conception and design, acquisition analysis and interpretation of data
- drafting and revising the article for peer review
- final approval of the version to be published

Best wishes,

James Evans.

With regard to the following co-authored papers:

Nicholas Medforth & Elaine Huntingdon (2018) **Still Lost in Transition?** Comprehensive Child and Adolescent Nursing, 41:2, 128-142, DOI: [10.1080/24694193.2017.1330370](https://doi.org/10.1080/24694193.2017.1330370)*

Nicholas Medforth & Elaine Huntingdon (2018) Found in Transition Comprehensive Child and Adolescent Nursing, 41:4, 237-254, DOI: [10.1080/24694193.2017.1323976](https://doi.org/10.1080/24694193.2017.1323976)*

I can confirm that Nick Medforth was the lead author on these publications and contributed at least 70% to the development, writing and submission.

This included:

1. acquisition of the commissioned project
2. substantial contribution to conception and design, acquisition analysis and interpretation of data
3. drafting and revisiting the article for peer review
4. final approval of the version to be published

I would be happy to provide any additional information as required.

Regards

Elaine Huntingdon

To whom it may concern

I confirm that Nick Medforth was the lead author on the publication - Medforth N, Rooksby K. (2017) **Enabling Young Service Users to Provide Feedback on their Experience: An Evaluation of the Pilot Implementation of Children and Young People Accessible Friends and Family Test in General and Dental Practices in NHS England South (South Central)**. Comprehensive Child and Adolescent Nursing 2018 Mar;41(1):42-57. doi: 10.1080/24694193.2017.1316789. Epub 2017 May 1. PMID: 29474801.*

Nick contributed at least 80% to the development, writing and submission of the publication. This included

- acquisition of the commissioned project
- substantial contribution to conception and design, acquisition analysis and interpretation of data
- drafting and revising the article for peer review

- final approval of the version to be published.

Should you wish any further information please do contact me and I wish Nick the best of luck with his continued studies.

With best wishes



Kath Rooksby

Senior Manager Integrated Personalised Care Team

NHS England South West

Hi Nick

I am excited to hear about your PhD by Publication and wish you luck with this. I am happy to confirm that you were the lead author on the publication below and contributed at least 70% to the development, writing and submission of the publication. This included:

- acquisition of the commissioned project
- substantial contribution to conception and design, acquisition analysis and interpretation of data
- drafting and revising the article for peer review
- final approval of the version to be published.

Medforth, N, Evans, J, Hills, M, Madden, H and Oyston, J (2019) ***Hearty Lives (Liverpool): a case study-based evaluation of a project designed to promote healthy eating and lifestyles in looked after young people.*** Adoption and Fostering, 43 (1). ISSN 0308-5759 *

If you need any more information from me, please let me know – I would be eager to support in any way I can.

Many thanks,

Hannah

13th July 2023

Dear Nick,

Please find the below statement to clarify my small involvement in your study.

I confirm that Nick Medforth was the lead author on this publication and contributed at least 80% to the development, writing and submission of the publication. This included,

- Substantial contribution to conception and design, acquisition analysis and interpretation of data
- Drafting and revising the article for peer review
- Final approval of the version to be published.

If you require any further information from me in this regard, then please do not hesitate to contact me.

Yours sincerely,



Caroline Boyle, RN, RCN, CCN, BSc Hons, MSc Advanced Practice, Pg Cert.
Programme Lead Specialist Practitioner Community Children's Nursing,
Senior Lecturer Public and Allied Health Liverpool John Moores University