

# **The influence of the nature of children's disabilities on societal reactions experienced by their parents**

## **Abstract**

This paper details a qualitative study which examined the influence of the nature of children's disabilities on stigmatisation experienced by their parents. To explore stigmatisation, semi-structured interviews were conducted with 22 parents of children with a range of disabilities. Findings highlighted that differential treatment was experienced by all parents, regardless of the nature of their children's disabilities. However, the *types* of reactions from others were influenced by three key factors; visibility of the child's disability, evidence of behaviour deemed to be socially inappropriate, and perceived controllability of the disability. Parents of children with Behavioural, Emotional and Social Difficulties (BESD) experienced intensely negative reactions from others, whilst other parents experienced much pity. The implications of these findings for policy and practice are considered, indicating that parents may be encountering stigma solely based on the nature of their children's disabilities. The paper concludes by stressing the importance of support outlets for parents.

**Keywords:** courtesy stigma; special educational needs; disability; parents; family; qualitative research

## Introduction

A longstanding concern has been the stigmatisation of certain groups of individuals, not least those with disabilities, who are often problematically deemed to possess “an attribute that is deeply discredit[ed]” (Goffman, 1968, 11). However the perceived *controllability* of a condition, and whether it is perceived to be behavioural or biological, is suggested to have a key influence on the consequent support or hostility displayed by others. Whether stigmas are perceived to be biological or behavioural in nature is crucial here as research has indicated that these attributions influence the perceived controllability of stigmas (Weiner, 2006; Hinshaw, 2005; Corrigan, River, Lundin, and Kubiak, 2000; Weiner, Perry and Magnusson, 1988).

For example, behavioural stigmas are perceived to be controllable (Weiner, 2006; Forsterling, 2001), in other words caused by a lack of personal effort (Weiner et al., 1988) and “brought about by choice” (Weiner, 2006, 19). Due to this, individuals with behavioural stigmas are viewed as being personally responsible for them (Dijker and Koomen, 2003). Reported examples of stigmas recognised as being controllable are mental illness and drug addiction. On the contrary, biological stigmas are viewed as uncontrollable and are therefore perceived to be out of the control of the stigmatised individual and based on genetic factors or accidents (Weiner 2006; Dijker and Koomen, 2003; Forsterling, 2001). Examples of perceived uncontrollable stigmas are blindness, physical disability and Alzheimer’s disease (Weiner, 2006; Forsterling 2001; Corrigan et al., 2000; Weiner et al., 1988).

The distinction between controllable and uncontrollable stigmas is important to make, as literature suggests that these differences in perceived controllability lead to variations in

reactions from others, and the support provided to stigmatised individuals (Mak and Kwok, 2010; Hinshaw, 2007; Forsterling, 2001; Corrigan et al., 2000; Menec and Perry, 1998; Weiner et al., 1988). For example, research has identified that individuals who are perceived to have *controllable* stigmas may be viewed negatively and shown anger, disgust or rejection, and are not given sympathy or offered help (Hinshaw, 2007; Forsterling, 2001; Menec and Perry, 1998; Weiner et al., 1988). This is in contrast with individuals who are viewed as having *uncontrollable* stigmas, who may encounter sympathy from others and are offered support and help, as opposed to anger and rejection (Weiner, 2006; Hinshaw, 2005; Forsterling, 2001).

The study reported in this paper therefore intended to apply the above theory to the context of Special Educational Needs (SEN), and explore whether SENs are deemed to be controllable, and the influence that perceived controllability has on societal reactions. Of specific interest here were the experiences of parents who had children with Behavioural, Emotional and Social Difficulties (BESD); an SEN which has the possibility of being viewed as a controllable SEN due to its parallels with mental health difficulties (particularly in terms of invisibility and the possible display of behaviour deemed to be socially inappropriate). However, the experiences of parents with children with SENs which were assumed to be biological were also important to examine, to make comparisons with parents of children with perceived controllable SENs.

### ***Stigma towards parents of children with SEN and disabilities***

When *children* with disabilities are of concern, it is usually their parents who experience stigmatisation from others. This is often referred to as courtesy stigma (Peters and Jackson, 2009; Hinshaw, 2007; Crawford and Simonoff, 2003; Gray, 1993). However, one group of

parents in particular have attracted much criticism and stigma; those who have children with BESD. An overwhelming wealth of research has reported that parents of children with BESD are courtesy stigmatised, as their children frequently display behaviour deemed to be socially inappropriate, yet their SEN is 'invisible' to onlookers (Broomhead, 2013; Mak and Kwok, 2010; Farrugia, 2009; Peters and Jackson, 2009; Blum, 2007; Ryan, 2005; Norvilitis, Scime and Lee, 2002; Gray, 2002). Chambres, Auxiette, Vansingle and Gil (2008) suggested that this is because when no visible cues are available to explain children's inappropriate behaviour, observers assess them in relation to the behaviour expected from typically developing children, leading to negative reactions towards children but most of all their parents. BESD also frequently conjures up images of parental controllability; that is, parenting, or rather 'ineffective' parenting, is assumed to be responsible for the onset of BESD in children (Francis, 2012; Ryan, 2010), leading to assumptions that BESD is controlled by the child or their parents .

For example Crawford and Simonoff (2003), as well as Harborne, Walpert and Clare (2004) reported how parents of children with BESD were regularly stigmatised due to their children's difficulties. In addition to this, Gray (2002) found that parents frequently experienced hostile staring and rude comments from others in public situations, when their children displayed behaviour deemed to be socially inappropriate. This was identified as being particularly traumatic for parents, especially when they were already embarrassed by their children's behaviour.

Other literature has identified that the enacted stigma experienced by parents of children with BESD is reflected in avoidance from others, which leads to their social activities and opportunities to interact with others being restricted, consequently having a negative impact

on friendships (Peters and Jackson, 2009; Gray, 2002). For example Peters and Jackson (2009), based on in-depth interviews with eleven mothers of children with Attention Deficit Hyperactivity Disorder (ADHD), found that mothers were not often invited to social activities and were unable to access social opportunities, because of reluctance from others to look after their children. As well as this, their friendships with other adults were strained due to the socially inappropriate behaviour displayed by their children. Koro-Ljungberg and Bussing (2009) found that this frequently led to parents socialising with other parents of children with BESD to not only ensure that their children's behaviour was understood, but also to attempt to normalise the behaviour in addition to gaining support. This reiterated the findings of previous research which identified that parents of children with BESD frequently restricted their socialising to other parents of children with BESD (Farrugia, 2009; Crawford and Simonoff, 2003; Gray, 2002).

However, it is important to refrain from theorising that courtesy stigma only occurs with regards to parents of children with BESD, although this is considerably underexplored. For example, Glogowska and Campbell (2004) interviewed parents of children displaying speech, language and communication difficulties (SLCD) and similarly found that parents felt courtesy stigmatised due to their child's SEN, and experienced avoidance from neighbours and others members of the public. On the other hand, these children with SCLD were of pre-school age and did not have official diagnoses, highlighting the importance of exploring this issue with parents of school-aged children with formal SEN diagnoses. A paucity of literature has therefore considered whether parents of children with SENs other than BESD are stigmatised. Instead, as highlighted above, much literature has focused on the courtesy stigma experienced by parents of school-aged children with BESD, thereby assuming that stigma is solely of significance in cases involving children with BESD. The potential

influence of the nature of children's SENs on societal reactions towards their parents subsequently warrants further investigation.

Based on this, the study reported in this paper explored experiences of differential treatment towards parents of children with a wide range of disabilities and learning difficulties. The research question under examination was;

- What are the perceptions of parents of children with SEN (both with and without BESD) regarding their experiences of stigma in relation to these children's difficulties?

In-depth insights into the influence of the nature of children's disabilities on the differential treatment experienced by their parents were elicited.

## **Methodology**

The study detailed in this paper was based on an Interpretative Phenomenological Analysis (IPA) approach, which provided the opportunity to explore key experiences of participants in a detailed manner (Smith, Flowers and Larkin, 2009). IPA is a stance adopted by the researcher which consequently informs the whole study, from the planning stages to writing up of the research (Smith et al, 2009; Larkin, 2006), and influences all methodological decisions made. It should therefore not simply be viewed as an approach to data analysis. Although deemed to be a 'young' approach to qualitative research (Larkin, Watts and Clifton, 2006, 105), IPA is informed by hermeneutics, phenomenology and ideography (Smith and Eatough, 2006), identifying that the methodology has well-grounded theoretical underpinnings. The study reported in this article was approached via IPA, as this perspective

is particularly relevant when investigating significant experiences in participants' lives (Smith et al, 2006). This is due to the perception that when a major event has occurred, participants will attempt to reflect on it in-depth, and IPA researchers can engage with these reflections in order to understand the phenomenon being explored (Smith et al, 2009). This was of key relevance for the current study, as parenting a child with SEN can be viewed as a transformational life experience (O'Connor et al, 2005). The area of SEN is also often sensitive and emotionally charged for parents (Lamb, 2009), therefore IPA was perceived to complement the research area.

Nevertheless, it is important to acknowledge criticism of IPA. Firstly, this approach requires participants to be articulate in order for them to engage with their experiences of a phenomenon at length, which Willig (2008) suggests restricts the applicability of IPA. On the other hand, this is not a problem specific to IPA; it also applies to many qualitative approaches where eliciting in-depth information from participants is essential. Secondly, IPA has been suggested to be too descriptive (Madill et al, 2005). However this has been disputed by IPA researchers, who identify that the conceptual comments made during analysis (where participants' responses are scrutinised and interpreted via psychological theory), move IPA away from a solely descriptive analysis (Smith et al, 2009; Brocki and Weardon, 2006).

Parents were approached via support and activity groups for children with SEN and their families, as well as via an online forum for parents of children with SEN, in the North West of England. A short overview of the study was placed on the forum, together with details regarding how parents could initiate contact (by sending a private message via the forum), if they were considering taking part. Participants were one father and 21 mothers of children with SEN, highlighting the reason for using the term 'parents' throughout this paper.

However, it is important to acknowledge concerns that the phrase parents is “gender-blind” (Traustadottir, 1991, 212), in other words it does not recognise the differing roles and experiences of mothers and fathers in terms of caregiving and educational responsibilities. Parents all had children formally recognised as having a disability or learning difficulty. As this study specifically intended to examine the influence of the nature of children’s disabilities on societal reactions towards their parents, it was important to ‘categorise’ parents in some way, based on their children’s SENs. Parents were therefore separated into four sub-groups based on the nature of their children’s difficulties. These sub-groups were as follows;

*‘with BESD’*; parents with children who displayed socially inappropriate behaviour as a characteristic of their SEN (more specifically children with Attention Deficit Hyperactivity Disorder, Oppositional Defiance Disorder and/or Obsessive Compulsive Disorder);

*‘without BESD’*; those who had children with an SEN which did *not* involve them displaying socially inappropriate behaviour as a characteristic of their SEN (in this study’s case parents of children with Dyslexia, Dyspraxia, Moderate Learning Difficulties, Down’s Syndrome, Cerebral Palsy, Speech and Language Difficulties, and Duchenne Muscular Dystrophy);

*‘visible SEN and socially inappropriate behaviour’*; parents of children with (in this study’s case) Down’s Syndrome and/or Severe and Profound Learning Difficulties, which frequently involved them displaying socially inappropriate behaviour but for which there was a visible explanation (in other words the children’s ‘different’ physical appearance);

*'classic ASD'*; parents of children with Autistic Spectrum Disorder (ASD) who displayed socially unusual behaviour (such as hand flapping, repetition of conversations, difficulty communicating and relating to others), but which was a characteristic of their developmental, communicative disability.

Although it may appear problematic to 'categorise' parents based on the diagnoses attached to their children, these distinctions were necessary as the study was exploring the influence of the nature of children's SENs on societal reactions towards their parents. 16 of the children had Education, Health and Care (EHC) Plans, whilst the remaining six children were on their school's SEN register and receiving SEN support (in other words receiving support from external services such as Educational Psychologist intervention or Speech and Language Therapy, Department for Education, 2015). The vast majority of the children of parents interviewed were male. Nevertheless, this does reflect the current situation, in that considerably more boys than girls were formally recognised as having an SEN in England during 2017 (Department for Education, 2017).

With regards to ethical considerations, the British Educational Research Association ethical guidelines (BERA, 2011) were adhered to when planning and conducting the study reported in this article. In terms of access, a key benefit of approaching parents via the internet was that it reduced pressure to participate, as well as reduced ethical risks, as their participation was based on them contacting myself. Written consent was provided by each participant, and ongoing consent was also sought from participants when contacting them to arrange interviews, as well as at the beginning of each interview. Participants were frequently reminded that they had the right to withdraw from the study before their interview, as well as any time up to fourteen days after their interview had taken place (as suggested by BERA, 2011 and Oliver, 2003). This was deemed to be particularly important for the study reported

in this article, in case participants discussed a sensitive issue during their interview which they later regretted or had not wanted to divulge (as highlighted by Kvale and Brinkmann, 2009). However, no participants withdrew from the study at any time. Finally, due to the sensitive issues under examination, participants may have become emotional during their interviews, which Applequist (2009) experienced when interviewing parents of children with SEN. Due to this, the researcher was prepared to terminate interviews if participants appeared uncomfortable, as maintained by Cohen et al (2011). Four parents did become upset and cried; they were consequently given time to compose themselves and then asked if they would like to continue with the interview, whilst also reiterating that they were under no obligation to do so (as suggested by the Applied Educational Research Scheme, 2009). All requested for their interviews to continue.

Semi-structured interviews with parents explored a range of issues regarding their experiences of parenting disabled children, with one particularly pertinent interview question being;

- Can you tell me whether you feel anyone treats you any differently because of *child's* SEN?

Participants were subsequently asked to identify who the individuals that treated them differently were, to discuss any specific experiences of differential treatment, and to reflect on how these experiences had made them feel. As can be seen from the above question, the term 'stigma' was not used, as it was deemed to be loaded and leading. Instead, the phrase 'differential treatment' was adopted. However, parents spontaneously used the term stigma during interviews.

With regards to data analysis, all interviews were transcribed in full and consequently analysed utilising the five-stage IPA guidelines produced by Smith et al. (2009). It should be noted that a case-by-case analysis was conducted. In other words, stages 1 to 4 were completed for each participant and stage 5 was only carried out once all interviews had been individually analysed. Stage 1 is referred to as immersion in the data, in other words reading and re-reading the transcript, as well as listening to the participant's audio-recording, to encourage familiarity with the participants' experiences. Stage 2, initial noting, resembled a free textual analysis where descriptive, linguistic and conceptual comments were made. During stage 3, emergent themes (succinct statements) were developed in order to summarise segments of comments made during stage 2. Furthermore, stage 4 involved searching for connections across emergent themes, resulting in a table of super-ordinate and sub-ordinate themes for the participant. Finally, stage 5 involved the combining and relabelling of themes, with the end result being overall tables of super-ordinate and sub-ordinate themes for each parent sub-group.

## **Discussion of findings**

Differential treatment was reported by *all* parents of children with SEN, although the *types* of reactions from others appeared to be influenced by the nature of their children's SENs, in addition to perceived controllability of the SEN, visibility of the SEN, and whether their children displayed socially inappropriate behaviour. Parents of children with BESD reported experiencing stigmatising and negative attitudes from the general public and friends (due to BESD being perceived as controllable, 'invisible' and their children displaying inappropriate behaviour frequently), whilst those with children with SENs other than BESD received pity and sympathetic reactions from others (as these SENs were perceived as uncontrollable and

often visible, with some also not displaying inappropriate behaviour). These emergent themes are considered below.

### ***Enacted stigma towards parents of children with BESD***

Many parents of children with BESD, of varying ages, experienced stigmatising attitudes from the general public and friends, and often talked of losing friends;

*Sarah ('with BESD' group):* we very rapidly stopped getting invited to parties, parents who had been friendly as he got older and it became apparent he was different were less friendly, I don't get invited to things on the same basis...there were people who couldn't move away quick enough

*Bethany ('with BESD'):* you feel excluded from your friends as well, I've got some friends who stopped inviting you out, it's not nice...they ask me if I've got my son before they invite me to their house, and if my son is with me they won't carry the conversation on

*Hannah ('with BESD'):* I'm trying to get him into the dentist and believe me it's taken me twenty minutes to get him out of the car into the dentist, and I'm dragging him, and you can see ten people standing there going 'what is going on?', and 'why is he behaving so badly?'

Parents of children with BESD experiencing courtesy stigma and receiving negative reactions or "attitudinal barriers" (Goodley and Runswick-Cole, 2012, 60) from the general public due to perceived controllability has been widely reported in previous literature (Francis, 2012; Mak and Kwok, 2010; Harborne et al., 2004; Gray, 2002). For example Harborne et al. (2004), based on interviews with parents of children with ADHD, identified the stigma

experienced by parents in public places, which led to them avoiding these places or feeling that they had to disclose that their children had ADHD.

However, the invisibility of BESD also appeared to have an influence on the reactions of the general public. For example, *Hannah* implied that her child's inappropriate behaviour at the dentist was not understood by others, due to the lack of visible explanations for his behaviour. Her son appeared to have been viewed as a typically developing child, and consequently his behaviour was viewed negatively, in addition to the negativity experienced by *Hannah* herself. This was reiterated by other parents of children with BESD, who reported experiencing intense pressure whilst out in public due to the 'invisibility' of their children's SEN;

*Melanie ('with BESD'):* his behaviour can become so appalling, but appear to be somebody just behaving very, very, very badly that erm I feel huge pressure...we have said to teachers in the past if this was a child in a wheelchair we would not be having this conversation...anything that isn't visible is much harder for people to understand

*Tracey ('with BESD'):* I think the worst thing about ADHD is it's so, you don't see it, it's so hard so people just feel like wringing their necks because you think he's just being naughty, but he's not being naughty

The significant influence of SEN visibility on stigma and pressure experienced by parents of children with SEN corroborates with past investigation (Francis, 2012; Ryan, 2010; Chambres et al., 2008; Blum, 2007; Thornicroft, 2006; Harborne et al., 2004; Gray, 2002).

More specifically research has referred to parents of children with ‘invisible’ SENs experiencing intensely negative reactions, contrasting with much pity towards parents of children with visible, physical conditions (Ryan, 2005; Crawford and Simonoff, 2003; Gray, 1993). For example, Blum (2007) identified how ten mothers of children with BESD considered themselves to experience greater stigma than mothers of visibly disabled children. This corroborated with my study, whereby several parents of children with BESD held the perception that pressure would *decrease* if their children had visible SENs, often expressing a desire for this;

*Bethany ('with BESD'):* no one wants anything wrong with their child but sometimes I wish he had more of a physical disability than what he's got because at least people would see there was something wrong, because people look at Isaac and he looks perfect, he looks perfect in every way

Here, it was clear that *Bethany* was highlighting a ‘preference’ for a child with a physical disability, as opposed to the unseen, hidden SEN that her son actually had. She emphasised that her son looked “perfect”, which negatively influenced others reactions when her son (frequently) behaved inappropriately. This was supported by parents of children with visible SENs (in the ‘without BESD’ and ‘visible SENs and socially inappropriate behaviour’ sub-groups), who were content with the visibility of their children’s conditions. This was due to their children’s inappropriate behaviour being expected by others, therefore providing an ‘excuse’, as well as reducing pressure and stigma;

*Rebecca ('without BESD'):* it's obvious visually and that's why I don't get reproachable looks because they think she can't help making a noise but another child [with no visible SEN] might get a tut

*Rachael* (‘visible SENs and socially inappropriate behaviour’): people expect his behaviour to be a bit erratic...because it’s visible

An interesting example of this was when *Rachael* (‘visible SENs and socially inappropriate behaviour’) stated how she felt “lucky” that her son had a visible SEN, despite his severe disabilities and health problems. This was a thought-provoking finding as it appeared that parents displayed ‘preference’ towards parenting children with visible SENs which were often accompanied by severe physical, learning and health difficulties, as opposed to a child with an invisible, often ‘less severe’ SEN; solely due to the visibility of it.

Secondly, the display of inappropriate behaviour by children with BESD influenced the reactions of others towards their parents, as well as negatively impacting on the actions of these parents’ friends. *Sarah* and *Bethany* illustrated above how they had lost friends and were not invited to social events, due to the nature of their children’s SENs and the negative impact that the SENs had on their children’s behaviour. *Bethany*’s case emphasised this, as it was the sole presence of her son that was the issue; if friends knew he would be accompanying her on social outings, they withdrew their invitations. This highlighted direct stigma towards these parents, solely due to them having children who displayed socially inappropriate behaviour, which supports previous literature (Farrugia, 2009; Peters and Jackson, 2009; Crawford and Simonoff, 2003; Gray, 2002). Nevertheless, it is important to acknowledge that *Sarah* and *Bethany*’s sons both displayed extremely inappropriate, and frequently aggressive, behaviour. Friends of *Sarah* and *Bethany* may therefore have been fearful of their own children’s safety if children with BESD accompanied them on social outings. This suggested that the *severity* of the socially inappropriate behaviour, rather than the display of inappropriate behaviour per se, was the key influencer on whether parents of

children with SEN were stigmatised. Although Gray (2002; 1993) identified that the severity of a child's condition influenced stigma towards parents, a paucity of recent literature has recognised this influential factor.

On the other hand, it is important to acknowledge that parents of children with BESD identified benefits of parenting children with invisible SENs when they behaved appropriately (supported by Gray, 1993);

*Michelle ('with BESD'):* if he's behaving well you wouldn't know there was anything at all wrong

*Ian ('with BESD'):* in the public domain you can't tell there's anything wrong with Oliver\*...at a first glance he's just a normal boy...'til he starts asking about what washing machine you've got [laughs]

In other words when children with invisible SENs behaved appropriately, they were viewed by society as typically developing children and did not attract attention. This identified the combined influence of SEN visibility and evidence of socially inappropriate behaviour on the intensity of stigma and pressure experienced by parents.

### ***Differential treatment towards parents of children with other SENs via pity and sympathy***

The experiences of parents of children with BESD regarding blame and pressure contrasted heavily with parents of children with SENs other than BESD. Parents of children with other SENs reported experiencing differential treatment from others but in the form of pity, sympathy or (what they deemed to be) patronising attitudes. Nevertheless, parents of children with visible disabilities also reported much staring. Although this kind of

differential treatment may be seen as less extreme than the reactions experienced by parents of children with BESD, sympathetic and patronising attitudes from others were severely disliked by these parents, potentially due to pity being associated with some sort of deficiency (Weiner, 1992);

*Catherine ('visible SENs and socially inappropriate behaviour'):*

people do stare and they can be rude in their staring

*Louise ('classic ASD'):* I encounter folk who put you on a pedestal like

'oh gosh, what kind of a life you must lead', I don't like any of that,

like 'oh you do such a marvellous job with him', it's patronising

*Abby ('classic ASD'):* they say 'oh you poor woman' and I can't stand

that, *I can't stand that*, you know 'oh how do you cope?', get a grip, I

can't stand that pity, I despise it to be honest, I don't want it

These findings are supportive of the research by Loja et al. (2012), who used the phrase "charitable gaze" (1) when referring to the "pity, curiosity as well as 'heroic' and positive views" (4) that non-disabled individuals displayed towards disabled members of society, or in my study's case those closely related to them. They also evidenced societal perceptions of children with disabilities as "tragically impaired", problematically in line with the medical model of disability (as highlighted by Goodley and Runswick-Cole, 2012 (55); Liasidou, 2008; Ho, 2004; Tregaskis, 2002; Llewellyn and Hogan, 2000); perceptions which parents strongly resisted.

Additionally, the quotations above demonstrate the influence of perceived controllability of an SEN, as well as SEN visibility and evidence of socially inappropriate behaviour on the

type of differential treatment experienced by parents. For example, several of the children of these parents often displayed socially inappropriate behaviour. However, in the cases of parents who had children with visible SENs and socially inappropriate behaviour, this behaviour was excused by onlookers due to the visibility and perceived uncontrollability of the SEN (in *Catherine's* case, Down's Syndrome). Furthermore, in the cases of parents of children with classic ASD, although 'invisible' the child's SEN was often revealed to onlookers, either via the child displaying socially unusual behaviour or parents informing others about the ASD. This therefore providing a certified 'excuse', and the behaviour of these children was again viewed as uncontrollable (as indicated by Thornicroft, 2006; Weiner, 2006 and Weiner et al., 1988). This led to stigmatising reactions being replaced by pity, sympathy and patronising attitudes (maintaining Cudre-Mauroux, 2010).

### ***Friendships with other parents of children with SEN***

The differential treatment experienced by parents of children with SEN led to some of them (not exclusive to any sub-group) actively seeking and forming friendships with other parents who also had children with SEN. This was due to the perception that similar parents were more understanding of the issues that they were experiencing as well as, according to *Sandra*, reducing pressure due to 'power in numbers';

*Hannah ('with BESD'):* we play and socialise basically with other families with disabilities, so your eccentricities and all the craziness you bring becomes normal and fine

*Kelly ('visible SENs and socially inappropriate behaviour'):* the people who we socialise with really have got a child with a disability, so they understand...if she's frustrated and she's doing something they're more understanding

*Sandra* ('classic ASD'): you do end up meeting people who have something in common with you, so if you're going to the park and take your autistic child with you, if they're there with their autistic child as well it takes the pressure off you both...the bigger the group the less pressure you feel, because you become the majority rather than the minority

On the contrary, several parents (again not exclusive to any sub-group) did *not* seek friendships with similar parents, some of whom were actively against doing so like *Sarah*;

*Sarah* ('with BESD'): it can degenerate into a very negative thing of everyone pouring out the sob story...you can also be defined by the disability and I've always wanted to avoid that

The above quotes revealed that homophily, in other words the importance of forming friendships with others due to sharing similar characteristics in this case having children with SEN (Gray, 1993; Robins and Rutter, 1990), was really down to the personal preference of parents. It was also influenced by whether parents were content with disability being the foundation of friendships; *Sarah* was actively against disability being the key characteristic to form friendships around, and therefore rejected forming friendships with other parents of children with SEN or attending support groups (as found by Ryan and Runswick-Cole, 2009, and Gray, 1993). This contrasted with other parents such as *Hannah*, *Kelly* and *Sandra*, who viewed their friendships with other parents of children with SEN as a key source of support and understanding. Parents of children with SEN seeking friendships with similar parents is consistent with much previous research (Goodley and Runswick-Cole, 2012; Salmon, 2012; Pratesi and Runswick-Cole, 2011; Goodley and Runswick-Cole, 2010; Farrugia, 2009;

Crawford and Simonoff, 2003; Gray, 2002). For example, Koro-Ljungberg and Bussing (2009) demonstrated how parents of children with ADHD sought friendships with similar parents in order to normalise their children's inappropriate behaviour (which links to the parent statements above), and to consequently manage the stigma and loss of other friendships that they had experienced.

## **Conclusion**

This study has identified that the *types* of societal reactions experienced by parents were influenced by the nature of their children's SENs, as well as perceived controllability of the SEN, visibility of the SEN, and evidence of challenging behaviour. It is concerning that the 'labels' of SEN given to children can have such a directly negative impact on the societal experiences of their parents. However, issues regarding reactions from others are difficult to overcome, as they are grounded in how observers make judgements based on the information available to them. As a child's BESD is not visible, but their challenging behaviour is, it is understandable why onlookers come to conclusions about 'naughty' children and subsequently stigmatise their parents.

The study reported in this article has highlighted that parents may experience much stigma and/or differential reactions from others, alongside the daily pressures and demands of raising a disabled child. Educational practitioners, as well as those who support children with SEN and their families, need to be aware of the additional societal perceptions and expectations placed on parents, in order to fully understand and attend to their needs and concerns. Issues regarding reactions from others are difficult to overcome, as they are grounded in how

observers make judgements based on the information available to them (Weiner et al, 1988). Instead of attempting to directly tackle this stigma, perhaps what would be more appropriate in the short term is to focus on supporting parents after they have encountered these reactions from others, or lost friends. This could be in the form of support groups, where many parents in my study found comfort and friendships (whilst acknowledging that not all did). Parents could potentially be connected via schools; for example Special Educational Needs Co-ordinators have the knowledge to connect parents of children with SEN together, although this would need to be conducted very sensitively. Additionally, wider development of online support forums, which could provide guidance on issues such as stigma and losing friends, could be helpful for parents who do not wish to engage in ‘face-to-face’ support groups. On a macro level, there is an evident need for policy to consider the needs of parents aside from the needs of their children (Warin, 2007), and to reinforce the importance of support outlets for parents of children with disabilities.

This study has contributed to the previous literature base by providing an in-depth, qualitative insight into the perceptions and experiences of parents of children with SEN regarding societal reactions. It was crucial that these sensitive, emotionally charged experiences were identified as they appeared to be key influencers with regards to parenting a child with SEN. The study also explored Weiner’s (1980) ideas regarding controllability and applied them to the field of SEN in a qualitative manner. Findings identified how the perceived nature of children’s difficulties and the labels of SEN attributed to them, conjured up perceptions of cause, controllability and consequent experiences of stigma and/or pity. The need for greater practitioner investment in, understanding of, and sensitivity regarding the lives of parents of children with SEN is subsequently recognised. An additional contribution to the literature base was exploring the influence of the perceived nature of children’s SEN on societal

reactions, via the inclusion of parents of children with varying SENs. This key sampling decision led to the identification of how differential treatment was a wider issue for parents of children with SEN, regardless of the perceived nature of their children's difficulties.

This paper has detailed a study which provided a qualitative insight into experiences of stigmatisation with parents of children with a wide range of disabilities and learning difficulties. These findings highlight how the diagnosis 'attached' to children with SEN and disabilities can have a profound impact on societal reactions towards their parents, and consequently emphasises the crucial importance of support outlets for parents.

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