

Children with SEND and the emotional impact on parents

John Holland , Gabrielle Pell and KIDS*

Children bring joy, new experiences and challenges into the lives of their families, and the focus of this article is on the often unrecognised emotional challenges and stigma experienced by parents of children with special educational needs and/or disabilities (SEND). This study involved a random sample group of 240 parents using a service in the Hull and East Riding areas of the UK. These parents filled in a questionnaire, the results of which showed that there were points of particular stress for some families, often involving their initial concerns when their children's difficulties were unrecognised, the diagnosis itself, and then obtaining support. In addition, for some families, this stress led to the breakdown of parental relationships. Significant areas of additional stress included parents having feelings of guilt and emotional strain, with experiences of isolation for the family and negative impacts on parental mental health. Furthermore, some parents revealed incidences of stigma and a refusal to accept diagnoses and concerns, even from within the wider family. Likewise, some parents found that family and friends were not sympathetic or supportive. Finally, a number of parents also described detrimental impacts on siblings and expressed concerns about the education of and future outcomes for their child.

Key words: parents, SEND, disability, stigma

*KIDS is a charity supporting children and young people with SEND and their families, delivering services throughout England.

Introduction

The effects of stigma on individuals that hold a stigmatising trait have been well documented. This article explores the phenomenon of the effects of stigma on the caregivers of children with special educational needs and/or disabilities (SEND), and how this can lead to emotional distress and further social stigma (Green, 2003).

Having a child with SEND means that, to some extent, the parenting role within the family is different to the one anticipated and desired (Ellis, 1989; Olsson & Hwang, 2001; Russell, 2003). There can be a higher prevalence of unmet psychological needs in parents, and a significantly higher financial burden (İnanç et al., 2018; Tunali & Power, 1993). These challenges occur in addition to the difficulty of having their concerns confirmed with a diagnosis (İnanç et al., 2018), through the sometimes permanent nature of the child's SEND (Jones & Passey, 2005). After the diagnostic journey, there is yet another potentially equally problematic one – that of obtaining support. Both journeys can create a plethora of challenges and impact on parents (Russell, 2003; Young, 2018), leaving them vulnerable to stressors (Jones & Passey, 2005; Tunali & Power, 1993). Case (2000), among others, argued that parents need opportunities to express and clarify their feelings and adapt to circumstances (Ellis, 1989; Jones & Passey, 2005; Olsson & Hwang, 2001; Russell, 2003). Much research focuses on the evident 'needs' of parents, but fails to establish what specific expectations parents have and whether these are ultimately achieved (Russell, 2003).

Clear references to SEND in education essentially began with the Warnock Report (1978), and the Education Acts that followed. Provision for children has gradually been refined, at first with Statements of special educational needs, and, more recently, with the 2014 Children and Families Act and the latest SEND Code of Practice (DfE/DoH, 2015) which introduced Education, Health and Care Plans. A primary purpose of the latest Code of Practice relates to the early identification of needs and to agencies working together from the stage of diagnosis. This coordination was intended to help parents and families with the logistics and the provision of support, although there is a continued need to examine and address the emotional impact on parents (Case, 2000).

This study highlights the challenges that parents experience as caregivers of a child with SEND. This does not devalue or disregard the numerous positive and pleasurable elements of parenting a child with SEND; its purpose is

purely to afford adequate consideration to the challenges expressed by parents within this study. Children are a source of joy, happiness and fun and our findings do not signify a lack of hope, positive outcomes or optimistic futures for families and children.

Methodology

The research was undertaken by a postal questionnaire of a random sample of 240 parents in the Hull and East Riding of Yorkshire area who used KIDS Services, a national charity that provides an extensive range of services for children and young people with SEND and their families. KIDS Services currently support over 13,000 families, delivering over 120 services throughout England, and work with approximately 80 local authorities.

Following initial work in 2008, the authors carried out another study in 2017 on parental perceptions of the 2014 Children and Families Act (Holland & Pell, 2017), and how their experiences could be improved. The 2017 study focused on a holistic view of parental experience, and compared the findings to those of the research carried out in phase 1, before the introduction of the Children and Families Act, to determine whether any progression or development has been made since the legislative changes. The data gathered in phase 2 indicated a high prevalence of unmet emotional needs for parents and the impact on families; this article seeks to offer this specific area more in-depth consideration.

The research gathered both quantitative and qualitative data, and parental comments generated themes which this article explores. Themes included parental guilt and blame, fear of the unknown, detrimental effects on social life and mental health, lack of understanding from those around the family, stressors, isolation and the effect on siblings.

The questionnaire from the 2008 study was replicated in 2017 to ensure continuity and elicit comparable data. Of the 240 questionnaires distributed in 2017, 187 responses were returned completed.

Results

Support at the stage of identification

There are key points when the emotional impact may be at its greatest for families. This is often during the early stage of identification and diagnosis (Case, 2000; Hodge, 2006; Russell, 2003). The process of diagnosis and assessment was a stressful experience for many of the respondents, often

compounded by the lack of perceived support and a disconnection in communication between services (Barnes, 2008).

Liz related that:

‘We knew something was wrong with him and the practitioners took 4 years to diagnose him. So it caused stress in the family home because we didn’t know how to deal with his meltdowns tantrum [and he] couldn’t talk etc.’.

Table 1 shows an increase in the percentage of families describing their support as being excellent or good over the two phases, increasing by 10% and 4% respectively. Families describing their experiences as unsatisfactory declined by 12% over the same period.

There is a significant disconnect between obtaining a ‘label’ for the child in order to secure support, which is a positive step, and parents feeling that their role is undermined by practitioners, which can be counterproductive and damaging (Hodge, 2006). This is perhaps why, within this study, despite families’ collective experiences showing a general improvement since the first phase, 38% still said that their experience was unsatisfactory, and here the elevated levels of scrutiny and inspection of parents, and especially mothers, needs to be considered (Goodley & Runswick-Cole, 2011).

With 38% of families expressing dissatisfaction, it can be concluded that there is still much work to be done in order to ensure that the balance of support and guidance does not result in professionals actually reducing or removing the power of parents. Our findings support Hodge’s (2006) view that, prior to diagnosis, and despite concerns, parents gain pleasure and joy from their parenting role; however, when their concerns eventually prompt professional intervention, parents feel disempowered despite only

Table 1: How well supported did you feel at the time of diagnosis?

Response	Phase 1 (%)	Phase 2 (%)
Excellent	7	17
Good	13	17
Satisfactory	30	28
Unsatisfactory	50	38

attempting to secure support. This must be addressed as a matter of urgency; diagnosis is well documented as a very complex and stressful time for families, and the services existing to support families should not be an additional stress factor.

Hodge (2006) claims that prior to a diagnosis, which is necessary for support, parents generally experience many benefits within their parenting role, and it is only once services become involved that they are presented with a somewhat unoptimistic and despairing version of their future. It is possible to deduce that additional stress during this often bewildering process, with increased levels of surveillance, might lead to feelings of dissatisfaction during the diagnostic process.

In the first phase of the research, nearly two-thirds of parents stated that family and friends provided the best support, with the remainder nominating either practitioners or support groups. This was reversed in the second phase, with perceived support from professionals and support groups together rising to over 60%, and that of family and friends reducing to 30% (see Table 2). These changes are statistically significant, and seem to evidence an increase in collaborative working between professionals and families, although may relate to earlier diagnosis, and earlier intervention, as intended by the new Act.

We must also consider the ‘deficit’ culture that still dominates many processes of support. As Hodge (2006) asks, are families truly more satisfied with professionals, or has the early intervention agenda meant that children are assigned a diagnosis and receive support earlier, so the perception is that things are improving, without perhaps adequate reflection on the negative impact that these ‘labels’ often produce?

Table 2: Who offered the best support to you at the time of diagnosis?

Response	Phase 1 (%)	Phase 2 (%)	Statistically significant
Family and friends	64	30	Yes
Professionals	21	42	No
Support groups	15	20	No
School		6	
No one		2	

It is also interesting that support groups are rated more highly as sources of support, perhaps due to the fact that they are more widely available or better known, especially at a time when social media is increasingly used. Nevertheless, this does not eradicate the need for improvements within professional–parental relationships (Hodge & Runswick-Cole, 2008). It could be argued that, despite the plethora of policies concerning professional and parental relationships, the power imbalance between parents and professionals is still a long way from being fully addressed. For this to be the case, Hodge and Runswick-Cole (2008) state that professionals should be willing to accept alternative perspectives, work in open-minded ways and abandon the notion that they are the only ‘experts’. This is easier said than done. It is of course necessary in some cases for professionals to hold a level of power; however, this needs to be utilised appropriately and clearly must not be exploited. Professionals must reflect on the power imbalance in each situation, so that meaningful and fair parent–professional relationships can ensue.

Green (2003) found that the perceptions and reactions of those around children with SEND can affect the children’s life experiences, as was found in this study, with additional consequences for the family. Parents often felt that family and friends were not sympathetic or supportive, by failing to accept parental concerns or consequent diagnosis, or by blaming and stigmatising the parents; a third of families felt that family and friends did not understand their situation. Within this study, the stress also affected some parental relationships, leading to separations.

In both phases of the research, parents gained emotional support through having a listening ear. Encouragement and emotional support were mentioned more often than any other type of support. Practical support suggests logistical support, although it is likely that these themes often overlapped and are not mutually exclusive (see Table 3).

Family and friends

As shown in Table 4, perceived effects on family and friendships were significant. Sixty percent of parents said that the identification and diagnosis of SEND affected their family and friends, and, when asked to elaborate, all but one described negative experiences. A further 17% reported a partial effect, making a total of over three-quarters of parents.

Table 3: How did the support help?

Response	Phase 1 (%)	Phase 2 (%)	<i>p</i> -value	Statistical difference?
Being listened to/empathy/emotional support	35	41	0.310	N
Practical support	20	19	0.946	N
Advice/information	17	26	0.050	Y
Referral to appropriate agency	15	12	0.396	N
Child being valued/someone talking to child	13	2	0.002	Y

Nearly a third of families thought that friends and family simply did not understand their child, and felt that they had lost friends or that some withdrew and ‘*drifted away*’ and stopped ‘*coming round*’ to see them, resulting in isolation. Examples include Tom, who said: ‘*My family didn’t understand*’, and Rita, who stated: ‘*Most of my family never understood my struggle or my child’s disability*’.

Guilt

Numerous studies found parents experiencing guilt, regardless of the nature of their child’s SEND (Broomhead, 2013; Francis, 2012; Hess et al., 2006; Tunali & Power, 1993). This guilt can develop into shame and self-blame (Broomhead, 2013; Hingley-Jones, 2005). Blame was highlighted as being an issue for parents during the diagnostic process, which was not helped when parents thought that they were ‘*blamed*’ by family and friends, practitioners and wider society.

There is a long standing Government focus on parenting and outcomes, with policy makers placing accountability on parents, especially mothers (Blum, 2007; Francis, 2012), to develop their parenting skills and responsibilities.

Table 4: Did the SEND diagnosis have an effect on family and friends?

Response	Phase 1 (%)	Phase 2 (%)	<i>p</i> -value	Statistical difference?
Did not understand	26	17	0.097	N
Caused stress	14	20	0.203	N
Caused isolation	14	22	0.109	N
Felt was to blame	10	3	0.034	Y
No effect	10			
Positive effect	10			
Frustration and upset	6	6	0.919	N
Depression/anxiety	7	1	0.24	Y
Embarrassed	1			
Made excuses	1			
Learned to sign	1			
Arguments/strained relationships		9		
Did not believe child had SEND		10		
Detrimental impact on siblings		9		
Fear unknown		3		

This has, perhaps, led to a culture of parental blame (Broomhead, 2013, 2014; Francis, 2012; Hess et al., 2006; Peters, 2011). Hingley-Jones (2005) explains this further in terms of the cycle of blame and pity often prevalent within the relationship between parents and practitioners.

Amanda said that she was '*Not feeling listened to, I felt stress[ed], like I was blamed for his difficulties*', and Chris said: '*We felt [like] failures and to blame*'.

Emotional strain

It is well documented that parents experience some emotional strain at particular times in their child's life, which can be elevated when a child has SEND (Cuzzocrea et al., 2013; Olsson & Hwang, 2001). Beresford

et al. (2007) describe the parents' journey of coming to terms with a child's diagnosis and condition as a constant emotional task. A typical comment was made by Tony, who said: *'It was the not knowing what was wrong for a few years'*. Parents often lacked information and emotional support, as expressed by Phillip, who said: *'We were not given the help we needed at first'*, and: *'We knew there was something wrong and nobody would listen'*. Facing these additional challenges often compounded parents' feelings of despair (Beresford et al., 2007). Owen said that he had concerns about *'My health and family stress'*.

Receiving a diagnosis of SEND can elicit feelings of loss for parents (Olsson & Hwang, 2001). This has been described as being similar to losses such as bereavement or divorce and can affect families by creating feelings of grief, anger, guilt and helplessness (Ellis, 1989). David, talking about friends and family after the birth of their son, said:

'Some people didn't know whether to send congratulation cards or not. I suppose they weren't sure if he was going to survive, this did hurt a little'.

Isolation

Contact a Family (CAF, 2011) researched the effects of isolation on parents of a child with SEND, finding that 65% of families felt regularly or continually isolated. This echoes many responses made by participants in our study who reported feelings of isolation and loneliness coupled with the severance of friendships. Interestingly, CAF (2011) found that 64% of participants felt most isolated at the time of diagnosis.

Kim remarked: *'I distanced myself and kids from my family and friends'*, and Sam said: *'I have limited friends now due to lack of time to do things they do'*. Likewise, Elaine said: *'Some of my friends became distant and my child lost friends'*, and Jane added: *'My family have little understanding of my child's condition, I feel so isolated'*.

Trevor summed it up, describing being *'very isolated'*, which seemed to be at least partly caused by a lack of understanding from families and friends and their uncertainty about how to respond. Clearly, friends and family often

did not know what to say and how to interact. Some found that friends would cross the road to avoid them rather than engage.

With increased isolation comes a subsequent decline in social life, with a reduction in social opportunities. These restrictions for parents and their inability to pursue their own personal goals can cause additional stressors (Olsson & Hwang, 2001).

These effects were apparent in our research, with parents speaking of the negative effect that the process of diagnosis had on their sense of identity and the subsequent detriment to their social life. Beresford et al. (2007) highlight the fact that aspects of parents' identity may diminish with their parenting role taking precedent (CAF, 2011), the outcome being that parents have less time and energy to spend on pursuing their own personal interests and relationships, again affecting their social opportunities.

Some parents noted this link. For example, James said: *'My social life suffered [and I was] upset'*. Linda added that she was *'unable to have the same level of social life'*, and Pauline stated: *'I don't go out'*. Similarly, Yvonne said: *'It shut down our social life for a time, as we found it hard to deal with in front of other people'*. Lindsey added: *'We have to plan everything and certain activities we just cannot do'*. Mike also related the sense of isolation for both the family and their son, saying: *'Our family did not help and he had no friends'*. Amanda said:

'Just having someone to talk to or [to] even know about a support group, but we were left on our own and had no people to talk to for support after diagnosis'.

Sharon stated: *'Everybody was very upset at the time; [we] did not know [if] there was any support or what to ask for'*. Likewise, Catherine said: *'I felt lonely and had no one in [the] same situation and no one to listen to me'*.

Mental health issues

Since stress was frequently reported, it is not surprising that mental health issues were also raised.

Many responses emphasised the fact that the process of identifying SEND difficulties increased stress levels, with a detrimental effect on parents'

mental health (Voos, 2017). The CAF (2011) research found that 72% of parents experienced anxiety, depression and relationship breakdown due to the strain associated with the isolation they felt during that time. Parents raised issues such as the separation between them and their child during hospital visits. Beresford et al. (2007) point out that, understandably, witnessing a child suffer pain or ill health is particularly distressing for parents.

Pauline described that *'My life was turned upside down, all my time was needed to help my daughter'*. Parents were often under what they described as *'constant stress'* and Danielle described how *'It was constant worry and a huge strain on us all on what to do and where to go next'*. Maggie said that there was a mixture of *'stress and grief'*, as parents were trying to negotiate their way through the challenges of the system and at the same time suffering through the *'loss'* of their perceived expectations for and of their child. Peter said that his family *'spent 6 months in hospital between Hull and Leeds for operations'*. Rick commented that *'We were really sad and emotional'*.

Almost half of the participants in the CAF (2011) study remarked that they had sought help from their GP either to access a counsellor or for medication. This was echoed in our research, with Eren stating: *'Before [their] diagnosis I was prescribed anti-depressants due to [being an] over protective first time mum with post-natal depression'*.

Stigma and refusal to accept issues

Some parents experienced stigma as family and friends refused to accept or believe that there was a problem. Brenda said: *'His grandmother refused to believe that there was a problem'*, and Diana stated: *'They wouldn't accept it was SEN instead of just bad behaviour'*.

Parental isolation caused by stigma and discrimination within family and friend support networks seems to be prevalent (CAF, 2011; Jones & Passey, 2005). Manago et al. (2017) explain that this is a daily occurrence for families, and that a lack of understanding or general unawareness about specific disabilities seemed to be the underlying cause. This was reflected in our research with, for example, Jackie saying that *'Some people didn't understand my daughter's behaviour'*.

There is some conflict as to whether it is the stigma that is perceived within families of children with SEND or the burden of care that can generate

negative outcomes for families (Green, 2003). This study cannot categorically support one particular notion outright, but it is evident that the additional stress of stigma is not conducive to positive outcomes for families.

Tina said that her wider family '*didn't believe or understand*', and George said that '*The grandparents did not agree*' in relation to his child's diagnosis of SEND.

This study anticipates finding support for the idea that families are complex and resilient units with unparalleled expertise in their own situation, and that it is often the additional external factors around the family that can lead to social stigma and subsequent negative outcomes (Green, 2003). Regardless of the challenges facing parents of a child with SEND, it must be recognised that they are juggling and managing incredibly complex situations that are often compounded by social stigma. If their parenting capacity has inadequacies, this should not erase their entire skill sets or undermine the strengths they possess in other areas.

Roy summed things up by saying that members of his extended family '*didn't believe or understand*', and Sue commented: '*They didn't believe me and [they] led a different way of life*'.

Our findings highlighted anxiety or fear about attending social events because of concerns about how their child would behave, with others describing their child's behaviour negatively. Nevertheless, the bigger concern was the perceived inability of their friends and families to be able to understand their child's behaviour; Paul said: '*People didn't know how to take him*'. This lack of social interaction for parents may be unsurprisingly increased when parents fear how people will react to their child (CAF, 2011). Rogers (2007) found that parents experienced shame when their child did not conform to societal norms in public, compounding feelings of isolation and of inadequacy.

An example given by Pat was that the '*extended family stopped inviting us to their homes or events due to our child's behaviour*'. Ricky said: '*I did not like to socialise with my friends and their children due to my child's behaviours*', and Pam explained: '*We don't get invited anywhere because of his behaviour*'. Similarly, Francesca said her child '*behaves poorly*', and Philip commented: '*My family cannot control [the child's] behaviour*'.

Parents found similar situations with friends and acquaintances. Steve said: *'We tried to tell people that our son had problems but no one listened'*, and Linda stated: *'Nobody understood'*. Some parents found that the stress associated with a delay in diagnosis caused issues for families; as Mary put it, *'[There was an effect] on all the family as she didn't get diagnosed until she was 5 years old'*. For another parent, it was possible to find friends but *'Some of them did not understand SEN and thought the child is [just] naughty'*. Interestingly, some parents showed some empathy with others; Vera's view was that *'They didn't know how to help'*: *'Not understanding what it was and we had to explain, people who had not had experience in this area often seemed to jump to the wrong conclusions'*.

In all, this study supports Green's (2003) view of families' complexity, resilience and expertise, and that stigma and negatives outcomes are often the result of external factors.

Family difficulties relating to isolation

CAF (2011) found that the isolation experienced by the family of a child with SEND can lead to friction and the breakdown of family relationships, and many parents reported that family life became more stressful and pressurised. Similarly, our research found that some parents experienced regular arguments as a result of strain and tension. William said: *'I lost friends [and it] had huge impact on my family and ended up splitting up with my family'*. These processes appeared to prompt parents to reassess their views; David said:

'I personally thought of autism before our assessment and diagnosis like a lot of friends and family thought [of me] as being over protective or hypochondriac, this caused a lot of arguments'.

As mentioned earlier, stresses within families had led to separations and divorce. Sam said: *'[It] put too much stress on the family and led to divorce'*. Likewise, Angela said: *'it put a lot of stress on the family'*, Martin commented: *'It was a big strain on me and my wife'* and Norman stated: *'it was a strain on our marriage, it was very stressful'*. Pat agreed and said that *'In all areas it affected everyone'*. Graham felt, at the time, that *'Stress [was] put on the family'*.

Siblings

The potential impact on parents and on their relationships was clear within this study, with significant effect on siblings, who had to adjust, and suffered losses comparable to the parents. This was in terms of receiving less attention from parents, especially during critical times, and difficulties in developing meaningful relationships with their brother or sister.

Parents hope that siblings will positively adjust to the new situation, be able to form meaningful relationships with their brother or sister, experience autonomy and feel like a valued member of the family (Beresford et al., 2007). In practice this is difficult to achieve, especially considering the contributing factors faced by families in these circumstances. Responses highlighted various additional challenges that had arisen within families, and Graham acknowledged that *'[It was] a difficult time with the other siblings'*.

Lottie's response was typical:

'I had 3 year old daughter as well, and was in and out of hospital due to seizures ... hundreds of them that no one could stop and I had to keep sending my [other] daughter to her grandparents'.

Ray said: *'It was a hard time for the family, especially his older brother as he had to stay in hospital for several months'*.

Parents often thought that siblings lacked attention, as the child with SEND needed so much support. Kate stated: *'I felt like my eldest daughter was pushed out and didn't have the time and attention she deserved, as it took a long time to get support and recognition'*. Richard said: *'The other children find it hard to understand [his] problems'* and *'his violent outbursts put a strain on me and his siblings'*. Reflecting this, Harry commented: *'Siblings found it hard to communicate with him'*. Rachel said that there was *'A lot of pressure especially on other siblings'*, and that their child with SEND could display *'behaviour towards siblings'*.

Schools

Russell (2003) describes the disparity between parental and school expectations as a barrier to achieving positive outcomes. When professionals, and in particular school staff, identify a child solely from a perspective of deficit, describing the child and his or her difficulties as the problem, this

clearly damages the parent–school relationship, leading to further feelings of inadequacy for parents (Russell, 2003). In relation to this, Roger said: *‘I felt people at school made my child feel not normal’*. Sylvia added that it *‘caused upset with other parents due to my son’s behaviour’*, continuing the theme of other people not understanding the child’s SEND issues.

The lack of support and understanding from some professionals came as a surprise to some parents, with Ray commenting: *‘Everyone was shocked and dismayed at the lack of support, knowledge, consideration by the very people in place to help’*.

The future

Some families spoke of the difficulties of imagining what the future held for them and their child, and the general uncertainty about this. These worries increase the need for emotional support for parents (Hess et al., 2006;

Table 5: What would have helped?

Response	Phase 1 (%)	Phase 2 (%)	<i>p</i> -value	Statistical difference?
Being listened to/ empathy/emotional support	31	26	0.406	N
Practical support	26	8	0	Y
Advice/information	17	28	0.023	Y
Recognition of problem	11	7	0.352	N
Referral to appropriate agency	11	5	0.112	N
Earlier diagnosis/early intervention/speedier assessments	4	5	0.787	N
Increased understand- ing and knowledge		11		
More appropriate provision		8		
Support for siblings		1		
Better communication between agencies		1		

Rogers, 2007; Russell, 2003). There is a wealth of research suggesting that when parents face such challenges, while modifying or altering expectations of their child's future, additional stress and anxiety can be experienced by families (Dobson et al., 2001; Russell, 2003). Fear was often expressed about the future, even in the longer term when the child was an adult, with parents contemplating their own aging. Lucy described this as '*fear of the unknown*' and mentioned concerns about transitions, such as '*Worrying about the future for him when going to secondary school*'.

The majority of parents felt well supported during the assessment stage. Seventy percent felt that they were included in the process and 65% felt 'listened to'. Table 5 gives insights into the minority of parents who thought that they could have been better supported. The need for more emotional support, such as 'being listened to', reduced to 36% over the phases and fell to second in rank order behind the need for advice and information. However, over a quarter of parents still reported 'being listened to' as an unmet need, which is relatively easily addressed by practitioners.

Conclusion

The issues discussed here will often impact on the quality of life of many parents of children with SEND (İnanç et al., 2018). However, despite the complexities and life-changing aspects of parenting, the role is mainly one of delight and satisfaction.

Ultimately practitioners are working towards the best outcomes for children, young people and their families, so it would be imprudent to overlook the emotional impact on parents. If children and young people are to achieve their aspirations, consideration needs to be given to their parents and carers in order to support and empower families holistically without depending on a deficit model which can be detrimental and counterproductive.

A family unit is more than a collection of 'needs' reliant on outside sources to 'repair and fix' – there is a complex dynamic of needs, hopes, aspirations, personalities, strengths and challenges that vary widely from family to family. There is no overall rule that can be used to address a plethora of unique and personal differences, within different families. Therefore, practitioners working with families need to recognise each family's unique circumstance and value their distinct experiences, with parents being afforded time to explore their own feelings and wishes within and outside their parenting role.

Jones and Passey (2005) found a correlation between parents who experienced autonomy and felt in control and positive about their parenting skills, and those that enjoyed and felt satisfaction through parenthood, with higher levels of coping strategies and optimism. This emphasises the congruence between positive parental experience and an increase in family cohesiveness and resilience (Jones & Passey, 2005).

Parents within this study felt that, in order for support to be improved, they needed to be actively listened to, and they highlighted the need for further empathy and emotional support, as well as access to better advice and information. These have the potential to create personal control and to give autonomy to parents to adapt and increase their parenting competence and perseverance where necessary (Jones & Passey, 2005).

In conclusion, most parents are keen to take control of decisions affecting their lives; if the family feels isolated, then self-doubt and concerns may become evident. In this regard, support groups, where parents can meet others going through a similar experience, and the availability of practitioners able to offer emotional support or formal counselling, would be useful for families.

Recommendations

The primary recommendation is that practitioners continue to recognise the emotional impact on parents of having a child with SEND, and realise that challenges for families do not relate solely to logistical, medical and educational support. In addition, practitioners need to recognise key times of stress for families, such as around the time of diagnosis, and potential effects on their family, their friends and their own relationships.

Related to this, parents need to be made explicitly aware of local and national support groups, both specific and generic, at the time of diagnosis and assessment. The practitioners involved should be aware that they have a key role in signposting other services to parents.

Finally, there is a need to ensure greater public awareness of the issues raised in this article and of the dangers of families becoming isolated.

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Address for correspondence:

Dr John Holland

Email: john.holland@john-holland-ep.co.uk

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