ORIGINAL ARTICLE

Whoever shouts the loudest: Listening to parents of children with disabilities

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Background: Elevated stress is common among parents of children with disabilities. The parents' perspective and evaluation of services have a significant impact on their well-being and adaptation to their child's disability and is a source of information for service improvements. This study explores parental perceptions of communication and collaboration between parents and health and education staff in the context of an imminent reconfiguration of disability services.

Methods: A qualitative study was conducted using four focus groups with parents (n = 24) of children with disabilities who attend various educational and health services.

Results: Thematic analysis revealed five key themes: Us versus them, lack of child/family centeredness, resources, keyworker and uncertain access to a complex system.

Conclusions: Parents want greater collaboration between parents and professionals. They identified a keyworker as a potential solution to the current system that is not child-centred. This would also lessen the burden associated with high levels of advocacy.

KEYWORDS
advocacy, disabilities, identity, keyworker, parental stress, parents

1 | INTRODUCTION

The perspectives of parents and caregivers are crucial to understanding how services are experienced by those receiving them (Cheak-Zamora & Teti, 2015). The parents' perspective and subjective evaluation of services are central to their well-being and adaptation to their child's disability (Robert, Leblanc, & Boyer, 2015). Many studies have focused on how parents cope with the stress associated with parenting children with disabilities. They face unique challenges because of the additional demands relating to personal care, management of adaptive behaviour, medical, financial and social needs (Kishore, 2011; Plant & Sanders, 2007). Increase in stress is associated with children's behaviour problems (Hastings & Brown, 2002) and the levels of support parents are receiving (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). The focus of many of these studies is on aspects of the parents' functioning, examining dimensions such as locus of control and coping style (Armstrong & Dagnan, 2011).

Parents and caregivers are both consumers and participants in the delivery of care. Families of children with disabilities have to negotiate complex relationships with professionals and service agencies, and these can be problematic with inconsistencies and conflict (Todd & Jones, 2003). Shearn and Todd (1997) point out that although service interventions can reduce the burden of care on parents, these relationships often come with additional parent work. This can include liaising with service personnel, planning access to respite services and the work involved in accessing information about appropriate services. These all constitute additional work and demands for parents. Some of these extra roles can involve a "time burden" on caregivers (McManus et al., 2011) in addition to the "care burden." Many disability services rely on the willingness and ability of parents to adopt informal caregiving roles that usually span the course of a child's life (Raina et al., 2004). Few studies have focused on the potential stress parents experience in their interactions with service providers.

Children with disabilities are increasingly likely to be educated within mainstream settings (McConkey, Kelly, Craig, & Shevlin, 2016). Multidisciplinary teams provide support to children with disabilities during their schooling, whether this is in special schools, special classes or in mainstream settings (McConkey et al., 2016). Greater access to support services in special school has been shown to influence parents' decisions in relation to mainstream provision: it is often the case that support services are easier to access in special schools (Clegg,
Murphy, Almack, & Harvey, 2008) as they frequently have access to the multidisciplinary team on site. Whichever type of educational setting their child attends, parents will experience frequent interactions with health and education staff. They must also negotiate the complex relationship that exists between both sets of agencies.

Communication between parents and schools has been identified as a significant source of stress for parents (Burke & Hodapp, 2014). Parents can feel frustrated with the jargon used by school staff (Hammond, Ingalls, & Trussell, 2008), by the excessive paperwork (Schrag & Schrag, 2004) and by the adversarial nature of advocating for their children (Fish, 2008). Similarly, communication with health professionals can also be a source of stress for parents of children with disabilities (Osborne & Reed, 2008).

Some countries have taken steps to legislate for improvements in collaboration between school staff and health and social service networks, based on the principle that collaboration between these agencies is essential to respond appropriately to the child's needs. However, evaluation of these policy initiatives indicates that parents still feel they are not given sufficient information about or precise contact information for, this service (Tétreault et al., 2014). Parents also reflected on the complexity of the system and the continuous battle to obtain services (Tétreault et al., 2014). In summary, the relationship between parents and professionals is crucial to many outcomes for children with disabilities (Dunst & Dempsey, 2007).

Parental experiences of health and education services have the potential to highlight areas which need to be modified or improved within the current service paradigm. This study takes place in a service undergoing radical reorganization. Multidisciplinary services for children with disabilities in Ireland are delivered by the health service and a number of health service-funded agencies. There is considerable variation across the country in the configuration of these services and the organizations which are tasked to provide them. The ‘National Progressing Disability Services for Children and Young People programme’ (Health Service Executive, 2009) was established by the Department of Health in Ireland in 2010. The central theme of this policy initiative was that all children with disabilities would receive support through an integrated service model which would allow children to be seen and supported as close to their home and school as possible, by generic disability teams. An emphasis on equity of provision across the country and across disabilities was cited as justifications for generic disability teams. There are some risks in moving to a more generic model. Generic services for children with disabilities have been criticized by parents as lacking the expertise required to work with children with complex needs and challenging behaviour (Wodehouse & McGill, 2009). Services that are highly rated by parents are often those that offer a high degree of expertise (Griffith & Hastings, 2014).

This reconfiguration of services is slowly being enacted across the country, but has yet to be implemented in the service area of this study. Before the generic teams were established, the present authors wished to examine the parents’ perspective on how the health and education services communicate with each other, what could be done to improve collaboration, and to get feedback from them on potential improvements that could be made to the way in which services communicate directly with parents.

### 2 | METHOD

#### 2.1 | Design

A focus group method was chosen to allow us to explore the experience of parents of children with disabilities have of multidisciplinary and educational service providers. The moderator’s guide (see Appendix 1) structured the questions asked in each of the groups; however, the richness of the data comes from the sharing of parents’ personal experiences and feelings with one another. Focus groups can support parents to feel more confident sharing their views about a service in a group rather than being interviewed on their own. They encourage open communication among participants and can capture novel issues and concepts. Focus groups can encourage greater disclosure than individual interviews (Beck, Trombetta, & Share, 1986) and may result in less bias as participants are less inclined to try to impress the interviewer when in a group (Vaughn, Schumm, & Sinagub, 1996). It is also a method that allows for the collection of rich, in-depth data about the subject and is particularly suitable in situations such as this, where the area is complex and under-researched (Sofaer, 2002). An additional benefit is the ability of the moderator to encourage participation and interaction between the group members.

#### 2.2 | Sampling

A purposive sample was recruited from parents of children with disabilities (Palinkas et al., 2015). A maximum variation sampling approach (Coyne, 1997) was employed to maximize the diversity of reported experiences, by inviting parents whose children attend a variety of educational settings, included preschool, primary school, post-primary school and special school. The educational services receive multidisciplinary supports from five different disability organisations, all of which are funded by the Health Service Executive, the public health service of Ireland. If parents indicated that they were interested in taking part in the focus groups, a research assistant contacted them with dates and made the arrangements for attendance.

#### 2.3 | Participants

In total, 24 parents (mothers: n = 18; fathers: n = 6) participated in the focus groups. Twenty-three participants were biological parents of a child with a disability, while one father was a foster parent of a child with a disability. All participants had English as their first language. Inclusion criterion was that the parent had a child with a disability: intellectual, physical or Autism Spectrum Disorder (ASD) currently accessing a public disability service. Four parents had more than one child with a disability, but three chose to discuss their experiences of one child only. In total, they reported on 25 children diagnosed with disabilities and attending a variety of educational settings. Eight children (32%) were attending a special school, five children (20%) were attending a special preschool, three children (12%) were attending a mainstream preschool, six children (24%) were attending a mainstream primary school, and three children (12%) were attending a mainstream post-primary school. The children’s ages ranged from 2 to 16 years. Boys (n = 22, 88%) were more represented than girls (n = 3, 12%).
1.1 Battle with professionals

Most parents reported a history of difficult relationships with professionals. They “battled with professionals” to gain access to services for their children (1.1.1). Many felt that professionals did not take the parents’ role seriously, and some felt dismissed by them (1.1.2). Some parents believed that professionals did not listen to them and did not appreciate their unique position in relation to caring for their child. Parents focused on encounters with professionals that were characterized by conflict and struggle (1.1.3).

1.2 Parental stress

The majority of parents who participated in the focus groups spoke about the negative emotional impact that battling with professionals for services had on them. It was an intense process for them. Many parents felt stressed and attributed this stress to parent–professional interactions (1.2.1). A number of the parents reported feeling exhausted at having to “fight for services” (1.2.2). Dealing with professionals left many parents feeling anxious and disempowered.

1.3 Advocacy

Parents acknowledged that advocating for their child was an important part of their role. Their advocacy techniques ranged from more passive methods to more assertive strategies. Some parents described how advocating aggressively with professionals changed their personality (1.3.1). They noted that some parents got their child’s needs met without having to actively advocate on their behalf (1.3.2). However, most parents agreed that “screaming loudly” was the most effective method of securing resources for their child (1.3.3). A number of parents acknowledged the negative impact this behaviour had on individual parent–professional relationships (1.3.4).

1.4 In-group membership

The majority of parents empathized with other parents of children with disabilities, and many expressed favourable attitudes towards all parents of children with disabilities. This was particularly evident when one parent asserted that the parents in the focus group knew more about their child’s specific disability than the medical professionals (1.4.1). Some reflected on how helpful they found participating in peer support groups and how much they learnt from other parents (1.4.2). They had a positive image of themselves as being essential to their child’s care. They referred to their specific roles as coordinator between health and education professionals and as advocate for their child (1.4.3). Parents noted the importance of talking to other parents to gain emotional and social support (1.4.4).

1.5 Divide between stakeholders

Many parents reported a divide between parents and professionals (1.5.1). They commonly referred to professionals and parents in the third person plural which highlighted the polarity between them. Many parents noted a further divide between health and education professionals and the subsequent lack of collaboration in service provision; some attributed this to power struggles between sides (1.5.2). They expressed a lack of knowledge about how professionals collaborated with each other, and a small number of parents believed that there...
were no collaboration strategies in place (1.5.3). Participants spoke of the valuable contribution that parents can make when working alongside professionals and expressed a desire for more unity (1.5.4).

### 1.6 Fortuitous outcomes

Parents frequently attributed positive experiences with professionals and subsequent outcomes to fortune (1.6.1). Many parents felt fortunate to have received services when they did (1.6.2) or to have unexpectedly met people who provided assistance to them (1.6.3) (Table 1).

#### Theme 2. Lack of child/family centeredness

### 2.1 Bureaucracy/box ticking

Many parents felt that the current system depersonalized their child and reduced them to numbers and categories (2.1.1). Some parents...
felt the system was system-centred rather than child-centred (2.1.2). A number of parents spoke of missing deadlines and having to wait until the following academic year to apply for resources again (2.1.3).

### 2.2 Unmet needs

A number of parents described initial uncertainty about which service their child belonged to (2.2.1) and a lack of trust in the system's ability to meet the needs of their child (2.2.2). Even when the parent explicitly communicated their child’s needs to the professionals, their child’s needs went unmet. This led to parents feeling disillusioned (2.2.3). Many parents felt that nobody knew their child or had their “child’s best interest at heart” (2.2.4). They felt that service provision lacked continuity and this resulted in an inability of professionals to meet their child’s needs (2.2.5). However, this was not the experience of every parent who participated in the focus groups. Some parents asserted that individual professionals were able to anticipate their child’s needs due to the professional’s familiarity with the child (2.2.6). A small number of parents also spoke of how their personal needs were not being met by professionals (2.2.7). These parents felt that professionals did not empathize with how the parent was feeling. One parent noted how cold, insensitive and detached the professionals acted towards her (2.2.8). Conversely, a number of parents reported a secure relationship with professionals in which their needs for support and advice were met. These parents believed that if they expressed a need for help, they would be listened to and supported by professionals (2.2.9) (Table 2).

### Theme 3. Lack of resources

Many parents felt that the state was not meeting the financial needs of disability services and this directly affected their ability to secure resources for their children (3.1). Most parents attributed lack of services to lack of state funding (3.2). However, one parent questioned why there was a resource issue considering the high levels of fundraising being done for the disability services (3.3). A number of parents reported feeling lucky that they had received services when there was apparently more funding available (3.4) (Table 3).

### Theme 4. Uncertain access to a complex system

#### 4.1 Navigating a complex system

Many parents found early experiences of navigating through complex disability services confusing and unpredictable. They reflected on the “hit and miss” nature of the system and found it difficult to navigate (4.1.1). Furthermore, a number of parents reported there was a lack of accessible information about the available services (4.1.2). This caused anger and frustration (4.1.3). Some parents spoke of going from service to service trying to “fit in” and professionals not knowing where to send them (4.1.4).

#### 4.2 Uncertainty around future changes

Many parents reported uncertainty around future changes in the disability services (4.2.1). Some looked to professionals for reassurance as
they felt unsure of how their child would be effected (4.2.2). A number
of parents expressed concern for their child’s future, and some were
fearful of a new system. Some parents were apprehensive and con-
cerned that their child would transfer to a new service and be forgot-
ten about (4.2.3) (Table 4).

Theme 5: Keyworker

In response to their unmet needs, parents highlighted a wish for the
employment of a keyworker (Table 5). A keyworker would fulfı́l a
number of functions and would provide continuity both for children
with disabilities and their parents.

5.1 Bridge between stakeholders

Most parents recognized that being a bridge between education and
health professionals was an important function of being a parent of a
child with a disability. Some found this stressful and insisted on the
desire for a connector and coordinator to regulate the services. They
called for this individual to help the parent through the mire of coordi-
nating between professionals (5.1.1).

5.2 Advocate

Many of the parents who participated in the focus groups reported
the need for someone to advocate on their child’s behalf. They ar-
ticated a wish for someone who would be “one step ahead of their
child” and someone who would take an active interest in the child’s
care (5.2.1). This person would speak or write in favour of the child
and his/her family (5.2.2).

5.3 Advisor

Many parents expressed the need for accessible advice on their child’s
abilities and available services. They wanted someone with whom they
could make informed decisions on the best course of action for
their child (5.3.1). A number of parents felt they were only given ad-
vice by professionals when parents were already struggling (5.3.2).
Parents seemed sceptical about the communication between health and education staff, and about the degree of collaboration between professionals. Despite this being a key question in the moderator’s guide, parents spent little time on this issue, giving much more attention to the themes of communication and collaboration between parents and professionals. As a result of having unmet needs, parents battled with professionals for access to services and supports. This theme is common among parents of children with disabilities in their interactions with services (Wodehouse & McGill, 2009). Parents in the current study referred to professionals and parents of children with disabilities in the third person plural, a finding also reported by Todd and Jones (2003). This indicated a clear divide between “us” and “them.” Furthermore, parents emphasized the polarity between parents and professionals. This corroborates previous findings where parents described communication with professionals as problematic and characterized by conflict (Todd & Jones, 2003). The division between “us” and “them” and the negative parental attitudes towards professionals may be explained by Social Identity Theory (Tajfel & Turner, 1979). This states that social categorization leads to in-group favouritism and out-group derogation as groups desire to achieve positive distinctiveness. In the current study, parents reported many instances where professionals acted in ways which contradicted parental beliefs. In cases where professionals acted in line with the child-centred approach and achieved positive outcomes for children with disabilities, parents minimized cognitive dissonance by attributing these experiences to
Parents in the present study were anxious about navigating a complex disability system. They felt there was a lack of accessible information about services and supports. They reflected on the unpredictable nature of the disability system and felt that there was no clear pathway or process. They were also apprehensive about changes in the system and looked to professionals for reassurance. While these parents were confident in their ability to advocate for their child, most attributed positive outcomes to fortune indicating that they relied on unpredictable events and people for information and support. The emotional consequence of this experience has been referred to elsewhere in which authors identified a lack of communication of information as a key stressor for parents of children with disabilities (Minnes, Perry, & Weiss, 2015). Kohler (1999) reported that 60% of parents of a child with ASD were dissatisfied with how agencies communicated with them. Lack of information was the most commonly cited unmet need among parents (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012). They reported that nearly half the parents of children with ASD were dissatisfied with how agencies communicated with them. The lack of available information and support has been linked to increased levels of hopelessness among parents of children with disabilities (Randall & Parker, 1999). Collaborative partnerships between parents and professionals are an important aspect of family-centred care. However, parents cannot act as experts in their child’s care if they do not have access to information about appropriate services and support (Jansen, Van der Putten, & Vlaskamp, 2013). Local authorities in England have been given responsibility for providing independent information and advice to parents of children with disabilities under the Children and Families Act (2014). In Ireland, there is no centralized body to provide information to parents, and the provision of services by many separate statutory and non-statutory organizations continues to contribute to the lack of transparent and clear sources of information for parents. Access to information could nurture parental empowerment (Tehee, Honan, & Hevey, 2009). The provision of an information booklet could act as a reference point, thus reducing parental uncertainty and distress. Robert et al. (2015) found that access to information helped parents of children with disabilities adjust emotionally, access services and improve management of their child’s behaviour.

The provision of a keyworker to fulfil a number of important functions was a consistent theme in all four focus groups and was recommended by parents in response to their difficulties. Parents wanted a nominated worker to alleviate the burden created by additional parent work. Parents anticipated that a keyworker would provide consistency in an ever-changing system, a finding which is supported by Brown et al. (2012). Parents in the current study argued that appointing a keyworker to a family could improve centralization and coordination of services. Parents hoped it would decrease the stress of having to navigate a complex system and battle with professionals. They highlighted the importance of consistency in the care of their child. Redmond and Richardson (2003) reported that mothers of children with disabilities recommended the employment of an advocacy officer who would...
coordinate and advise parents on appropriate services. These mothers noted the need for counselling and support for parents. Parents in the current study also desired access to someone they could talk to about the difficulties they experience. This is a recurring theme in the literature (Osborne & Reed, 2008), and it has been argued that appointing a keyworker may enhance communication between parents of children with disabilities and professionals and reduces the inconsistency of interactions with services (Holt & Kirwan, 2012). Carlson, Armitstead, Rodger, and Liddle (2010) reported that being supportive, encouraging, approachable and friendly were professional attributes important for creating positive parent–professional interactions. This appears to reflect qualities of a secure base as outlined in the attachment theory literature (Bowlby, 1988). A secure base is provided through a relationship with one or more sensitive and responsive attachment figures who meet a person’s needs and to whom the person can turn as a safe haven, when distressed or anxious. Much of the research to date on the importance of providing service users with secure attachment relationships has focused on mental health services and individual service users (Goodwin, 2003; Holmes, 1993). Adshead (1998) outlined how mental health professionals could nurture temporary secure attachment relationships via “good enough” professional listening, sensitive responses to distress and consistency of input. Little is known about providing a secure base to parents of children with disabilities; however, the attributes described above could inform how professionals interact with parents. Parents of children with disabilities experience a great deal of stress in adopting an enhanced advocacy role. The secure base relationship could offer support and reduce burnout.

Keyworking is a recent addition to Irish disability policy and legislation. The National Health Strategy (Department of Health and Children, 2001) proposed the appointment of keyworkers to coordinate services for children with disabilities. This intent was strengthened by provisions in the EPSEN Act (2004) and the Disability Act (2005). UK-based studies have shown that families with a keyworker experience less stress and have a better quality of life (Sloper, Greco, Beecham, & Webb, 2006). Despite this, research indicates that less than one-third of families of children with disabilities in the UK have access to a keyworker (Greco & Sloper, 2004). No comparative national figures exist in Ireland, but in our experience, keyworking is only available in a very limited number of services, and usually only in contexts with high staff-to-client ratios, such as early intervention services. It is interesting to note that in one study exploring the implementation of the keyworking (Mukherjee, Sloper, Beresford, & Lund, 1999), each staff member was nominated as the keyworker for one family, in addition to their normal professional role. In many of the services contributing to the current study, if each member of the multidisciplinary team was assigned to one family, around 1% of families would have a keyworker. One of the factors which may inhibit the provision of a keyworker could be the lack of specific funding for the keyworker role, despite policy recommendations. This raises important questions about who can be the keyworker, how they can work across agencies, and how to balance the needs for keyworking with the demand for therapeutic services for children with disabilities.

4.1 | Limitations

There are a number of limitations in this study. First, 24 parents reported on their experience which is a small number in comparison with the total number of parents of children with disabilities accessing services. Despite this, there was a reasonable consistency between parental experiences discussed in all of the focus groups. Second, it is acknowledged that self-selected participants open up the potential for bias given that they are more likely to have stronger negative or positive opinions and they are more likely to want to assert them. In addition, sociodemographic information such as parental marital status, socio-economic status, level of education and ethnicity was not recorded. While generalizability was not the aim of the study, these factors may have an influence on individual parental experiences. For example, a recent study has found that the socio-economic status of a parent of a child with a disability significantly influences their knowledge and use of services and their perceived unmet needs (Pickard & Ingersoll, 2015). Despite these limitations, many of the findings in the current study replicate and build upon other published results.

4.2 | Future research

This study focused on how parents experience disability services. We have not explored how the professionals experience the relationship with parents. In particular, a greater exploration of how professionals identify themselves in relation to parents of children with disabilities could facilitate a better understanding of the impact of both advocacy and activism on professionals. If group processes among the parents, such as those posited by Social Identity Theory, result in parents focusing on negative aspects of the service or the professionals they have interacted with, how will this be experienced by the professionals themselves? What influence might this have on job satisfaction and potentially burnout? This exploration has the potential to improve our understanding of the parent–professional relationship.

We chose to use a focus group method for this study, as this allowed us to gather rich data about the parents’ shared experiences of disability services. However, parent advocacy narratives are complex and sometimes contradictory, often emotive and may be suppressed in conflictual group settings. An alternative methodology, such as individual semistructured interviews, would allow for the exploration of individual parent attitudes in finer detail and delineate factors which influence the frequency and intensity of advocacy behaviours.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.
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APPENDIX 1: MODERATOR’S GUIDE

Introduction

Thank you all for attending today and agreeing to be part of this parent focus group session.

The purpose of these sessions is to hear your views, as parents of children availing of both health and education supports, on the collaboration that exists between staff working in both areas. We want to know (i) what is working well and (ii) what is not working well and (iii) we want to get your suggestions on improving practices going forward.

The focus group session will be for 1.5 hr and conducted by me—(name/background.) I have been asked to carry out this research by the Education & Health Working Group, and I am not part of the group involved in the roll-out of *Progressing Disability Services for Children.*

As you have been told, the sessions will be audio-taped but please note that all your comments, views, suggestions will be transcribed following today’s session and all will remain anonymous when the findings are presented. The findings will go back to the Education & Health Working Group, and the intention is that information gathered from these sessions will inform practices going forward.

Questions

1. What is working well between education and health staff?
   - Probe questions: Can you give examples of practices that work well? Can you state what is not working well? Can you give suggestions on improving collaboration between education and health staff?

2. How well do children move from one setting to another?
   - Probe questions: Can you give examples of practices that work well? Can you state what is not working well? Can you give suggestions on improving practices going forward.

3. What information and training have you had that is helpful?
   - Probe questions: What examples have you of good practices?
   - Probe questions: What training is going well? What training/information would you like to receive? Any ideas on training/information sessions that would be useful?
4. What could be done to improve collaboration between education and health staff?

Probe questions: Why do you think education and health staff do not collaborate more with each other? Any suggestions on improving contacts?

5. In an ideal world, what would you put in place to ensure education and health staff work together to provide the supports children need?

Probe questions: What would go on your Most Important List? What needs to be addressed immediately?