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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 children'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 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%).

2.4 | Ethics

Ethical research committee approval was obtained, and parents gave written, informed consent. All procedures performed were in accordance with the 1975 Helsinki Declaration and its later amendments.

2.5 | Procedure

The groups were moderated by two research psychologists who were not employed by the services. They explained their neutrality at the beginning of the meeting and encouraged an open debate among the parents. The moderators did not know any of the parents prior to the focus groups. Each focus group lasted 1½ hr, and a semistructured moderator's guide was used. The questions were chosen by a steering group, and identical questions were asked in every focus group session. Discussions were audio-recorded.

2.6 | Data analysis

Digital audio files from the four focus groups were transcribed verbatim. Data analysis was guided by principles of thematic analysis (Braun & Clarke, 2006). First, both authors did a naïve reading of all transcripts to become familiar with the data set. Initial codes, categories and subsequent themes were generated by each author and compared for consistency. In line with an inductive approach to thematic analysis, codes and themes were data-driven and did not fit into a pre-existing coding frame (Braun & Clarke, 2006). In a series of face-to-face meetings, the authors collapsed or refined similar themes. Dependability was supported when authors decided by consensus on the major themes to be reported (Lincoln & Guba, 1985).

3 | RESULTS

In this section, results are reported according to themes. Five principal themes were identified, and four of these themes contained subthemes. The key themes were as follows:

- Us versus them
- Lack of child/family centeredness
- Resources
- Keyworker
- Uncertain access to a complex system

Theme 1. Us versus them

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). Dealings 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

TABLE 1 Representative quotations for Theme 1: “Us” versus “them” (Social Identity)

1.1	**Battling with professionals**
1.1.1	…it’s definitely a battle, everything is a battle
1.1.2	And an example of what Sue said I experienced that as well I was told shut up, I didn’t know what I was talking about and listen to the professionals.
1.1.3	But then all of a sudden it was almost as if it was our word against hers for a while they wouldn’t believe you, yeah…if someone had your child’s best interest at heart rather than you constantly battling all these individuals
1.2	**Parental stress**
1.2.1	We can’t cope because we need, we‘re so stressed out trying to fight for services for our child.
1.2.2	I am sorry now but I am a bit weak and I don’t have the strength to stand up to them.
1.3	**Advocacy dimension**
1.3.1	I would be kind of a quiet person but I do find that since I started ringing, I can ring maybe three or four times a week now at this stage and I’ve got a bit more of a backbone. I do see a difference
1.3.2	It just happens that they just meet the boxes at the right time and they get to the right places but it’s not that the parents push for it.
1.3.3	Whoever shouts the loudest
1.3.4	…because I have been very very vocal. I mean I have got a lot of people on my side. I had the school tormented…You get nas…, not nasty but angry…I am a pain in their sides I know I am.
1.4	**In-group membership**
1.4.1	Even the way they speak and I sound silly like but when you go to meet professional people, they are inclined to use these words and you know, in a sense, we know what we are doing but you don’t have a clue. You’re only a parent. But I’ve met doctors and they’ve looked at me because I know more now about my child’s syndrome and you would and you would [pointing at other parents] than a lot of the doctors out there.
1.4.2	You learn a huge amount from the other parents there. It’s absolutely invaluable.
1.4.3	I think the parent is left as coordinator between the teachers, between the doctors, between the therapists involved.
1.4.4	Yeah, to talk to other parents in the same boat…and it’s such a relief
1.5	**Divide between stakeholders**
1.5.1	There is such a disconnect between teachers and parents and staff – for example, this focus group is a parents group `is separated from the focus group for the teachers from the focus group for the allied health care
1.5.2	Some kind of divide between the management of the school and the management of the services mmm a bit of power play between the two of them. Nobody really has the best interest of him at heart other than the parents
1.5.3	I’d said the school, the two are completely separate. I would say the two are completely separate. There isn’t a link, in my experience, between health and education. You might bring in some of your suggestions to the school to be built in to part of this. But there is no formal link in my view between health and education.
1.5.4	But I think that the parent’s voice and viewpoint is just as valuable as the professionals and we all need to listen to each other.
1.6	**Fortuitous outcomes**
1.6.1	He was lucky I suppose she got in to early intervention because she had significant needs like that’s what they were saying because I brought her for speech and language therapy and then she kind of was saying like oh I think she probably needs a bit of OT… But, so, when she got in to the early intervention that was great and she was getting OT she was getting SLT and she was getting help with her social skills and that led her on to [name of school] so she, it was luckily, it was a lucky kind of course of action
1.6.2	but the fear I know for parents who have kids on the spectrum, like we have been so lucky because well, some of us, I have been lucky because I think we came along, when there was a bit of money around
1.6.3	I got a wonderful person from [name of service] by chance I happened to be speaking to somebody someday in the supermarket and they said go try [name] out of [name of service]…but if I hadn’t by chance met this particular person I don’t know where I would be today

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

TABLE 2 Representative quotations for Theme 2: Lack of child/family centeredness

2.1	**Box ticking/bureaucracy**
2.1.1	Go to work and think well I've ticked the box and that's it…he's just a file, he's just a number. It doesn't mean anything to them.
2.1.2	You have to slot in with the system. It's not child-centred or around the child's needs… It's about how do we basically not spend as much as we possibly can.
2.1.3	Everything is already put in place in March of 6th class for that child going into Secondary in September and if you are a day late you have to wait another year
2.2	**Unmet needs**
2.2.1	So you know, no organisation will claim him and say yeah he's ours. We'll look after him.
2.2.2	And I don't expect that the services to adequate either as he moves forward I expect them to be very inadequate
2.2.3	But as I said there is no communication. We… we communicated our specific needs, we communicated the difficulties the child had and he was still thrown in at the deep end and nobody was told. What was the point?
2.2.4	Nobody has the child's best interest at heart
2.2.5	She's a very shy child when you meet her and like it's like every time it's like, trying to break the ice with her, trying to get to know her you've that then for maybe 4 or 5 weeks stopped now for 6 months. Go back and meet a different person again same routine, you know what I mean? it's just that they're only getting to know you now and we'll see you again in another 6 months and it will be all over again
2.2.6	He's absolutely brilliant. He's one step ahead every time. He's better than a parent. He's better than a mam or a dad. He's one step ahead for [child's name] the whole time.
2.2.7	Not knowing that parents have anxieties. They have expectations…So I just feel zero support for parents
2.2.8	They go to college with an idea of what they would like to do and they chip away at your humanity or your feeling side or something inside in college because you are not supposed to have feelings for or understanding for what the parent is going through, or what the child is going through more importantly. It's like, well it is just like this now and that is the way it is. You are supposed to pick up the pieces and get on with it.
2.2.9	Oh no I was very, very lucky with the health services they're very good to me. I'd be lost without them… I will have the help if I ask for it. I know I will because I don't think they would leave me down.

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

TABLE 3 Representative quotations for

Theme 3: Lack of resources	
3.1	That's the way our kids are being treated by the government and the parents. The fact is they are saving 3 billion a year the government and they are cutting SNA's
3.2	You can say if a problem arises and they could do with more resources in the school as well but it comes back to resources then again a lot of the time.
3.3	I would like to know or I would like more communication on the resource issue. Not really clear why there's that resource issue
3.4	We have been so lucky because well, some of us, I have been lucky because I think we came along, when there was a bit of money around

TABLE 4 Representative quotations for Theme 4: Uncertain access to a complex system

4.1	**Navigating a complex system**
4.1.1	So it was completely hit and miss along the way. Nobody knew my child and so hopefully I've landed in the right place. But going through all that along the way, they didn't know where to send us.
4.1.2	There's no say, not even a like a course outline. This is [name of service], these are the services we provide, this is the training associated with, and this is where, you know, you should be in a years' time.
4.1.3	There's no process which would help because you're frustrated and angry because you don't know (a) what to do (b) what's going on (c) where your child is in the entire process.
4.1.4	It is still a hit and miss thing… trying to find the right place and that's probably been the experience of most of us…But going through all that along the way, they didn't know where to send us
4.2	**Uncertainty around future changes**
4.2.1	We were told initially it is September and I am now hearing on the grapevine that it has all been shelved again and it will be another year before the roll it out. And it was supposed to be January
4.2.2	Is it going ahead? Is it going to roll out? You don't know?
4.2.3	They're not going to be just thrown into a new system and forgotten about. Or that it's the wrong type of care they're given. Do you know, so I'm kind of fearful of the change really.

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 concerned that their child would transfer to a new service and be forgotten 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 fulfil 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 coordinating 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 articulated 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 advice by professionals when parents were already struggling (5.3.2).

TABLE 5 Representative quotations for Theme 5: Key worker

5.1	**Bridge between stakeholders**
5.1.1	I just think in an ideal world, if every kid regardless before they are even diagnosed if there are going to be some difficulties/disabilities, whatever you want to call it. If they had a keyworker, a keyworker who will be able to help the parent through that mire of coordinating between the school, the physio, the doctor
5.2	**Advocate**
5.2.1	If you had someone who would say "yes, [child's name] needs physiotherapy, he also needs that…" what is the best for him to do it.
5.2.2	There's a teacher put in place and she will contact the parents… I can't see why they can't do that in the majority of mainstream schools, special schools, one person put in place who knows your child knows my child. And they could pull this child's file today and what do they need, who am I going to contact, what do they need and start a file of that child themselves.
5.3	**Advisor**
5.3.1	Someone who you could go to for advice. What is he capable of, is he capable of independent living or what services are out there? Whether it's these care homes or whatever just to get someone who has all the options to present to you knowing your child and saying I think this is the best option, what do you think? Or these are the alternatives.
5.3.2	And then for each transition from school, to secondary school, you need to transition from each stage. Someone there to say this is what is available, this is where you are heading, in time, not when you are struggling.
5.4	**Secure Base**
5.4.1	That there will be somebody there for the children to talk to in the school that there will be something set up for them. Maybe that same person can be a contact person for parents that ok if you have problems if you have, if you are not sure of anything ring this person.
5.4.2	His care worker knew him in there, she knew him really well do you know. But they knew him like… it's gone so disjointed now that nobody really knows your son now. Nobody knows your child that's going in to view them.
5.4.3	You are not supposed to have feelings for or understanding for what the parent is going through
5.4.4	Could there be a conn … a contact person between these groups. Maybe there's a way that either the HSE themselves can organise a, ok there will be a middle person between the groups so that this person could coordinate and say ok what are you doing on this side and what are you doing on this side. And maybe it can be an independent person that will say ok, ok these are the things that we feel that you could have improved on or and maybe that same person can be a contact person for parents that ok if you have problems if you have, if you are not sure of anything ring this person

5.4 Secure base

A number of parents envisioned the keyworker listening to their concerns and supporting them in their role as parents of a child with a disability (5.4.1). Some parents felt that professionals were unfamiliar with their child (5.4.2). A small number of parents felt that professionals did not empathize with them and dismissed their need for reassurance and advice (5.4.3). To remedy this, many parents called for an available person to take a family-centred approach to service provision (5.4.4).

4 | DISCUSSION

Partnership between parents and professionals is a key element of family-centred care, and in recent years, documenting parental experiences has become an important source of information for service planning and provision (Redmond & Richardson, 2003). The present study explored how parents of children with disabilities perceived the health and education staff communication and collaboration with each other and with parents. Five dominant themes emerged: *Us versus them*, *Lack of child/family centeredness*, *Resources*, *Keyworker* and *Uncertain access to a complex system*. Many of the findings presented are consistent with previous studies (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; Hammond et al., 2008; McManus et al., 2011).

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 fortune. Parent–professional partnerships are vital for the inclusion of children with disabilities. Factors that make for successful collaboration between parents and professionals have been identified. Parette, Brotherson, and Huer (2000) highlighted factors such as trust, respect, communication and cultural sensitivity. In the present study, parents desired a collaborative relationship characterized by mutual cooperation consisting of shared expertise, shared information and shared decision making. Despite this, the present study illustrates that there is a gap between the wish for effective collaboration and actual practices. Whether the new generic disability teams can provide improvements in communication and collaboration remains to be seen.

It has been documented elsewhere that parents of children with disabilities often adopt enhanced advocacy roles which involve fighting or battling with professionals (Read, 2000; Ryan & Cole, 2009). Todd and Jones (2003) suggested that mothers of children with disabilities who challenge professionals are aware that they might provoke negative reactions but still view their actions as "good mothering". Parents in the current study reported engaging in varying degrees of advocacy. For them, the advocacy role may have advanced to a high level of frequency and complexity as a result of parent–professional interactions. Some parents reported waiting for professionals to approach them with information while other parents were more assertive. These parents advocated on behalf of their child and supported other parents in their advocate role. Furthermore, some parents reported being aggressive to professionals in an attempt to get their child's needs met. Their behaviours fell within a continuum with passive techniques at one end and overt aggressive actions at the other. This is similar to the internal activist continuum proposed by Ryan and Cole (2009). They developed the concept of internal activist to encompass the wide range of advocacy behaviours adopted by mothers of children with ASD. They referred to instances where these mothers battled with professionals and lobbied local politicians. They argued that this enhanced advocacy role could be interpreted as a form of internal activism as it is focused solely on behalf of their own child rather than on children with disabilities more generally. They visualized a continuum with advocacy at one end and activism at the other. Some parents in the current study did lobby on behalf of their child. This lobbying may act as a precursor to broader external activism with a shift in focus to campaigning for change outside the family (Ryan & Cole, 2009). As a result of enhanced advocacy demands, some parents in the current study reported high levels of stress and burnout.

The shortage of resources was a consistent theme among participants. In previous studies, parents expressed dissatisfaction at the lack of services available to children with disabilities (Redmond & Richardson, 2003). Parents in the current study reported that there was a lack of uniformity and consistency in service provision. They reported that access to services was haphazard and they commonly experienced administrative delays and bureaucracy. Parents concluded that services were system-centred rather than child-centred and attributed unmet needs to lack of state investment. However, contrary to parental beliefs, there has been an increase in investment into public disability services (OECD, 2016) but this may have been offset by the increasing numbers of children accessing those services (Health Research Board, 2015).

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, pervasive development disorder (PDS) or intellectual disability were not satisfied with information pertaining to available services. Furthermore, when parents did receive information, they felt it was inconsistent (Read, 2000). 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 reoccurring 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: What examples have you of good practices? What are the barriers when a child is moving from one setting to another? What could be done better?

3. What information and training have you had that has been helpful?

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?