

# **The double-edged sword of vulnerability: explaining the persistent challenges for practitioners in supporting parents with intellectual disabilities**

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## **Introduction**

The aim of this paper is to explain the persistent barriers and challenges faced by health and social care practitioners in supporting parents with intellectual disabilities within the context of a growing body of international research that has begun to identify good practice in supporting this group of parents. The paper draws on evidence from a Scottish study that aimed to identify available supports for parents with learning disabilities, via a national survey and in-depth interviews with professionals. While the focus of the study was on Scotland, a small country with around six million people and approximately 5000 parents with intellectual disabilities (Authors et al, 2016), many of the findings resonate with wider international research that has placed emphasis on the importance of taking a strengths-based, whole family approach to the provision of support for parents with intellectual disabilities (see for example Wade et al, 2007; Llewellyn and McConnell, 2002). The paper adds to our existing knowledge by explaining *why* variable practice and barriers remain in the provision of support for families, despite growing awareness of and consensus around “what works”. It achieves this by taking a theoretically innovative approach that draws on a care ethics perspective combining this with theories of vulnerability. It is argued that constructing parents with intellectual disabilities as inherently “vulnerable” and in need of “care” reflects negatively on their capacity to parent thus impacting on the support that is offered to them. The paper does not make claims to effectiveness, although it does identify good practice and draws on research that has evaluated different types of parenting support. Nor does it draw on the experiences of parents with intellectual disabilities

themselves although the authors have done this elsewhere (Authors, 2009; Authors, 2012). This should be considered a limitation of the paper. We begin by setting out the existing evidence base on parenting support before explaining the theoretical framework that informed the argument developed here. We will then present findings from the Scottish study, using these to illuminate and explain the particular challenges that have emerged around implementing good practice.

### **Background to the study**

Estimating the number of families affected by parental intellectual disability has proven difficult because there is no universally agreed definition of intellectual disability and Governments, policy makers, service providers and practitioners are likely to operationalise different definitions in different contexts (Cooper et al, 2016). This is exacerbated by a reliance on self-reporting by individuals or carers which can be problematic due to the stigma associated with the label (Ho, 2004). For the purposes of this paper, the definition of intellectual disability is that set out by the Scottish Government in their national strategy, *the Keys to Life* (Scottish Government, 2013). It states that someone with an intellectual [learning] disability has a “significant, lifelong condition that started before adulthood, which affected their development and which means they need help to understand information, learn skills and cope independently” (Scottish Government, 2013: 5).

The lives of parents with intellectual disabilities are often characterised by social isolation, poverty, discrimination, poor self-esteem, relationship difficulties and unemployment (Authors, 2012; Wade, Mildon and Matthews, 2007, Llewellyn and McConnell, 2002). It can be argued that these complex circumstances combine with a diagnosis or label of

intellectual disability to make parenting challenging for this group of parents. This often manifests itself in over-representation in the child protection system (Cox et al, 2015), with estimates suggesting that between 40 and 60% of parents have their children removed after being assessed as being unable to meet an adequate standard of parenting (Wilson et al, 2013). Parents with intellectual disabilities are often thought to be neglectful rather than wilfully harming their child (Authors, 2012), although there is concern that these parents often have to meet stricter criteria than other parents when being assessed and are judged by unrealistically high standards (Tarleton, 2007).

According to Llewellyn and McConnell (2010), parents with intellectual disabilities have to work hard to prove they are able to parent and often struggle to overcome the oppression caused by the label and the “systematic barriers that flow on from beliefs that intellectual disability means ‘less than’” (Llewellyn and McConnell, 2010: 326). Like other groups of marginalised parents such as young mothers they attempt to create ‘positive parenting narratives’ (McDermott and Graham, 2005) in order to be perceived to be doing things in line with social expectations (Llewellyn and McConnell, 2010). These ‘resistance strategies’ (Pacheco and McConnell, 2017) attempt to challenge the cultural stereotype of women (or parents) with intellectual disabilities as passive, dependent and in need of protection that underpins assumptions about people with intellectual disabilities being unfit parents.

Despite these efforts, parents with intellectual disabilities still find themselves subject to decision-making where IQ scores are used instead of appropriate parenting assessments to justify intervention or the removal of children (Feldman and Aunos, 2010). For example, Sigurjonsdottir and Rice (2017) found that family courts tend to make potentially inaccurate

judgements about parenting capacity and risk of harm to children based on parental intelligence. They argue that this is due to cultural bias and a tendency to associate parental learning disability with assumed parenting deficiencies. They suggest that an imbalance of power between parents and the child protection system has resulted in “the aggressive and sometimes unjust removal of parents from their children” (Sigurjonsdottir and Rice 2017:549). We wanted to better understand the reasons for these continued inequalities by exploring the challenges that professionals face in supporting parents with intellectual disabilities.

### **Supporting parents with intellectual disabilities: an overview of existing international literature**

To address the research questions, we began by mapping out the existing international evidence on supporting parents with intellectual disabilities. This evidence suggests people with intellectual disabilities can and do become ‘good enough’ parents when appropriate support is in place. The Scottish Government (2008) suggests that ‘good enough’ parenting involves being able to provide basic physical care, love and affection, security, guidance, boundaries and age appropriate responsibility and independence. The concept has been criticised for lacking clarity (Choate and Engstrom, 2014) although it recognises the need to establish a baseline for assessing parenting skills, thus providing the opportunity to identify areas where skills and knowledge can be nurtured and developed. Such a model of parenting is subject to criticism from writers such as McDermott and Graham (2005) who argue that mothering (or in this case parenting) is a socially constructed category that is produced through regulatory discourses aimed at controlling behaviour.

Evidence-based programmes that have been tailored to meet the needs of parents with intellectual disabilities have been shown to be effective in supporting parents to develop their parenting capacity (Bauer et al, 2014; Feldman, 2004; Booth and Booth, 2003). They build on the skills parents already have and provide accessible information to help parents' understand the skills being taught. Repetition of tasks and undertaking these in the familiar home environment are very important (Feldman, 2004). Such programmes are cost-effective but do little to address the social isolation experienced by many parents (Tarleton and Porter, 2012; Booth and Booth, 2003).

Parents themselves report valuing group-based support programmes that bring together parents who have shared similar experiences to help them develop parenting skills while building their social networks and promoting their self-advocacy skills, helping them to be more assertive and recognise their own strengths (Booth and Booth, 2003). Programmes that combine home-based learning with group-based work (Tarleton, 2014) seem particularly effective. The evidence base for such programmes is growing and they have been shown to improve parent and child interactions, child development, behaviour and language acquisition for children and the wellbeing, effectiveness, self-esteem and confidence of parents (see for example Macbeth et al, 2015; Puckering et al, 2010; Scourfield et al, 2014).

Wade et al (2007), Aunos and Pacheco (2010), Llewellyn and McConnell (2010) and Collings et al (2017), among others have argued that family centred practices that harness strengths and preferences and promote collaborative decision making are crucial when working with parents with intellectual disabilities. Crucially, Wade et al (2007) argue that since the late

1990s there has been a shift from professional centred to family centred practice with an emphasis on family strengths and supports rather than exclusively child focused approaches to intervention. They draw on the work of Dunst et al, (1991), Dunst et al (2002), and Neff et al (2003) to identify the key features of family centred practice. They suggest that it involves promoting family decision making capabilities and competencies with an overall aim of strengthening family functioning and wellbeing. Family centred practice that facilitates parental involvement and early intervention has been found to lead to better developmental outcomes for children (Dunst, et al, 2002). Parents themselves talk positively about family-centred practice (Collings et al, 2017) and are more likely to be favourable to interventions carried out in this way (Wade et al, 2007). Crucially family centred practice recognises that relational qualities (such as respect for families) and participatory qualities (such as home based interventions and accessible assessment processes) are as important as educational interventions. Family-centred approaches help to build relationships between professionals and parents and there is some evidence to suggest that when there is congruence in the views of parents and professionals the need for formal or compulsory intervention (usually in the form of child protection measures) is lessened (Tarleton and Porter, 2012).

Despite the growing evidence in favour of taking a whole family approach when working with families where one or both parents has an intellectual disability, a number of barriers to implementing this approach remain. These include a lack of knowledge among professionals about the availability of appropriate services and supports for families (Sigjonsdottir and Rice, 2017), but importantly, also relate to assumptions made about the capacity of people with intellectual disabilities to parent, which often result in a crisis

intervention model guided by risk (Booth and Booth, 1993; McConnell, et al; 2002; Llwellyn et al, 2003). Stmadova et al (2017), in a study of attitudes, knowledge and experiences of social welfare practitioners in the Czech Republic found that most professionals held negative assumptions about the parenting capacity of parents with intellectual disabilities which then had a major impact on the support offered to them. Such attitudes suggest a presumption of incompetence and McConnell et al (2002) argue that they promote a pessimistic approach that prevents workers from observing families' strengths and promoting family connections.

### **Theoretical framework: Vulnerability and the ethics of care**

To better understand these assumptions about parenting capacity, we take as our starting point the suggestion that in most cases a parent with intellectual disabilities must be viewed as vulnerable in order to access the support and services they need to parent appropriately. This is particularly true in light of the increasingly stringent eligibility criteria that have been put in place to limit access to services as a result of austerity measures (Lymbery, 2012). With this label of vulnerability comes a lowering of expectations about that individual's capabilities and their capacity to parent. Using Scotland as a case study, Sherwood-Johnson (2012) argues that current Scottish policy (as set out in the Adult Support and Protection (Scotland) Act, 2007) is based on an assumption that vulnerability is caused by factors inherent to 'disability, mental disorder, illness or physical or mental frailty' in particular contexts, suggesting an interaction between individual traits and the broader social context the individual operates within.

Related to this, Speirs (2008) helpfully distinguishes between emic and etic approaches to vulnerability. The etic perspective sees vulnerability as something inherent to the individual that can only be measured through objective assessment by another person (usually a professional). It is the result of a series of internal and external deficits that make a person more susceptible to illness or harm. Vulnerability, according to this perspective is separate from the environment and is viewed as a personal attribute or behaviour. This way of understanding vulnerability leads to a tendency to focus on individual weaknesses rather than strengths, encouraging the individual to focus on what they cannot do rather than what they can in order to receive services (Fawcett, 2009).

From the etic perspective, vulnerability can be viewed as a highly paternalistic and to some extent oppressive concept. Fisher (2012) suggests that those people classed as vulnerable have fewer opportunities to have their voices heard, to enter a contract or to seek social justice. In other words, they have less opportunity to exercise their rights as citizens (Rowe, et al, 2012). This would suggest that responses to vulnerability result in greater marginalisation, ironically placing people at even greater risk. In addition, Hasler (2004) argues that assessments of vulnerability are used to justify over-protective and custodial care of disabled people (and their children) and to legitimise the exclusion of disabled people from the decision-making process, all of which is highly relevant for parents with intellectual disabilities.

The emic perspective on the other hand does not see vulnerability as an inevitable consequence of someone's gender, socio-economic status, ethnicity or disability (Speirs, 2008). Rather it focuses on the reality of an individual's day-to-day life and the potential for

danger and challenge that each day might bring. It situates the individual in their broader social context and encourages consideration of the factors that might work together to make someone more likely to be vulnerable. Crucially, it encourages cognisance of how this might be experienced from the individual's perspective. The emic perspective suggests that vulnerability is something that can be experienced by everyone. Beckett's (2006) influential argument is important in this respect. She contends that all humans are vulnerable in relation to a wide range of risk factors as well as to new forms of social exclusion. She suggests that a new approach is needed that avoids marking out certain marginalised groups as 'other'. In light of this, we contend that the application of an ethics of care approach (as described below) can help to reframe these debates around vulnerability in a more inclusive way that recognises that vulnerability is part the human condition (Tronto and Fisher, 1990). Acknowledging this helps to remove the dichotomous distinction between the *"normal", 'decent' and 'equal' citizen...and other dependent people who do not fall under the category of equal treatment, but who should be seen as the object of care and charity"* (Tronto and Fisher, 1990: 19). The "othering" of parents with intellectual disabilities in this way is likely to have significant implications for their right to parent as we argue later in this paper.

An ethics of care approach can shed light on some of the complexities around supporting parents with intellectual disabilities, and thus inform the manner of support provided. Of particular importance is the shift that an ethics of care approach takes from a binary approach (independent/ dependent; not vulnerable/ vulnerable; male/ female and so on) to one which has a relational ontology at its heart, focusing on the concept of inter-dependence (Sevenhuijsen, 2008), and the responsibilities that all humans have for one

another. It acknowledges power inequalities and difference within existing social arrangements and highlights problems with existing care arrangements where care givers are positioned as having more competence and expertise than the person receiving care (Tronto, 1993).

Kittay (2011) argues that if we begin to see all persons as moving in and out of relationships of dependence (or vulnerability) through different life-stages and conditions of health and functioning, the fact that disabled people often require the assistance of a care-giver becomes the norm, allowing a more egalitarian and mutually respectful approach to be taken. Fisher (2008) takes this argument one step further by arguing that an ethics of care approach can be linked to struggles of social recognition (Honneth, 2001; Fraser and Honneth, 2003) because it is embedded in relationships of inter-dependence where diversity is valued and importantly, the voices of marginalised groups are heard. This necessitates a shift in the way health and social care services are delivered to involve the sharing of power between service users and providers, acknowledging the value of experiential knowledge acquired in the private sphere of the family (Fisher, 2008). This has important implications for the delivery and provision of services for parents with intellectual disabilities as will be discussed in the remainder of this paper.

## **Methods**

The study discussed here gained ethical approval from the relevant University ethics committee and was conducted in line with the ethical guidelines of the Joint University Council Social Work Education Committee: Code of Ethics for Social Work and Social Care Research and the Social Policy Association Guidelines on Research Ethics. The names of

individuals or organisations have not been included in this paper with the only form of identification being a participant number.

As outlined in the introduction, the aim of the study was to identify available supports for parents with intellectual disabilities living in Scotland, highlighting areas of good practice as well as the barriers that continue to exist in the provision of such support. In Scotland the international evidence discussed above is reflected in the good practice guidelines for supporting parents with intellectual disabilities published by the Scottish Commission for Learning Disabilities in 2009, and refreshed in 2015 (SCLD, 2015). The guidelines set out the key features of a supported parenting approach, yet at the time of the research no information was held nationally about the range of supports and services that were available for parents with learning disabilities. Therefore an online survey was constructed using *Qualtrics* software (<https://www.qualtrics.com/uk/>) (see also Snow and Mann, 2012). The survey collected basic demographic information around role, sector employed in and service user group worked with before going on to explore the referral process (including the process of identifying parents with intellectual disabilities), eligibility criteria and the nature of the work undertaken with parents with intellectual disabilities in more detail. The survey asked participants to provide examples of what they considered to be good practice as well as considering barriers to providing support for parents with learning disabilities. A review of completion data suggests that the survey took approximately 20 minutes to complete. The data generated by the survey was stored in the password protected qualtrics system. Only one of the researchers had direct access to the system.

The survey was distributed across all Local Authority (32) and Health Board (15) areas in Scotland via a number of key networks and professional bodies. A snowballing technique was then utilised to forward the survey to relevant organisations identified by initial respondents. The survey was distributed to approximately 300 people and a total of 42 completed surveys were returned, representing a response rate of approximately 14%. Although online surveys offer the advantage of being relatively cost effective to undertake and usually result in quick response rates and a lower level of non-response (Van Selm and Jankowski, 2006), the achieved response rate of 14% was relatively low. This may be due to the use of external mailing lists where we did not have direct access to participants' contact details for data protection reasons. This meant that we were dependent on others distributing the survey and then following this up on our behalf. There was also some concern that the databases were not always well updated and this was further hampered by a lack of centrally held data. Despite these difficulties, a reasonably good spread of professionals completed the survey, as detailed in the findings section below, although the lack of centrally held data makes it impossible for us to estimate whether the numbers of health, social work and third sector staff who completed the survey is proportionately representative of all of those working in Scotland. It is therefore possible that those who chose to respond to the survey were already well attuned to issues faced by parents with intellectual disabilities and this will have impacted on the overall representativeness of responses received.

Based on an analysis of the responses to the survey, we identified four geographic areas where greater levels of activity in supporting parents with intellectual disabilities appeared to be taking place. Follow up interviews were carried out with thirteen key informants

across these areas. As part of the survey, participants were asked to indicate whether they would be willing to take part in a follow up interview. Key informants were recruited on this basis and a purposive sampling strategy was adopted to ensure a careful selection of participants according to job role, professional expertise and geographical area (Miles et al, 2014). This ensured representation across health (6), social work (2) and third sector organisations (5) although this depended on the agencies that were taking the lead in providing support for parents with intellectual disabilities in each area. Thirteen interviews were carried out. We felt confident that we had reached “saturation point”, (Saunders et al, 2018) whereby interviews were conducted until nothing new seemed apparent. Malterud (2012) argues that it is difficult for researchers to claim to have reached a total and final picture. She argues that it is more important to establish “an adequate and information rich sample providing coherent stories firmly grounded in empirical data” (2012: 801). Our sample included geographical spread and professional diversity and analysis suggested the data was rich and informative.

The purpose of the interviews, which lasted around 45 minutes, was to explore in more depth the ways in which services and supports were currently being provided. This enabled the identification of good practice as well as recommending areas for further development. The interviews provided an opportunity for key informants to expand upon the themes that emerged from the analysis of the stage one data (Bryman, 2003). This allowed the researchers to explore the extent to which the emerging themes from the survey made sense to respondents from a practice perspective, a form of “member checking” to explore the reliability of the results (Birt, 2016).

Prior to being interviewed, participants were emailed an information sheet and asked to sign and return a consent form. The authors conducted all of the interviews and did not have a prior relationship with any of the research participants. All interviews were audio recorded, with the respondents' permission and fully transcribed by members of the research team. Each transcript was given a code, stored securely (on a password protected system) with all identifying information removed and stored separately in order to preserve anonymity. The transcripts were coded manually (see below), no software coding system was used.

### ***Data analysis***

The survey generated quantifiable data that were analysed using basic, descriptive statistics generated via the qualtrics package to provide simple summaries about the sample and the various areas under exploration. A significant amount of the data collected in the survey was qualitative in nature given the aims of the study to identify good practice and gaps in provision. Data from the survey and key informant interviews was therefore analysed thematically (Miles et al, 2014) using the six key phases set out by Clarke and Braun (2013). A first stage of analysis took place with an initial reading of each interview transcript as soon as it was completed alongside a reflective process whereby the researchers identified issues that had seemed particularly salient after each interview. This allowed any necessary modification of interview schedules to allow particular areas to be explored in more detail. This was followed by the more systematic coding process that took place after all interviews were complete.

Qualtrics reports and interview transcripts were then read independently by the researchers and a process of open coding took place. This generated two lists of initial codes that were

then compared for areas of agreement and divergence between the researchers. The lists were then reviewed and refined to form a comprehensive list of codes that was grouped together using axial coding, which involved identifying connections and relationships between open codes. Braun and Clarke (2006) describe a theme as a coherent and meaningful pattern that is relevant to the research question. For example, the theme *“identification of parents”* involved grouping together codes on *“learning disability v learning difficulty”*, *“formal diagnosis”*, *“being on the borderline”*, *“eligibility criteria”*, and *“benefits and challenges of labelling”*. At the end of this process five key themes were identified: identification of parents with learning disabilities; early intervention; supports for parents with learning disabilities; accessible information; and joint working.

These themes were then cross-checked with coded extracts from the transcripts, as well as across the entire data-set (corresponding with stage four in Braun and Clarke’s framework). To enhance rigour, we followed a process of re-contextualisation (Malterud, 2012) where we returned to our original transcripts to ensure the coded data made sense in the context of each individual interview. In order to guard against bias, we ensured that this process involved a systematic search for data that might challenge the emerging findings. We maintained a reflexive stance throughout this process by systematically recording our decision-making and being clear about the tacit assumptions that influenced this. Mauthner and Doucet, 2003 argue that it is crucial that we understand how our personal and academic biographies influence our interpretation of research data. We therefore questioned whether our findings challenged our pre-conceptions by positioning ourselves in the process as researchers with many years of experience in the intellectual disabilities field with a deeply held commitment to social justice.

The emerging findings were subsequently presented at a series of national events to which all known participants were invited to ensure that they were able to comment on their validity. It was not possible to ensure all survey participants were able to be invited given the anonymous nature of the data collection process. The findings were also presented to a national network of parents with learning disabilities and associated professionals for their consideration. The key themes were agreed and confirmed at each of these events.

## **Findings**

Analysis of the survey was based on 47 completed survey returns from which there was a spread of disciplines (social work, psychology, midwifery and law) and job roles (manager, frontline practitioner, development worker). Table 1 below provides a breakdown of the job roles of the 27 respondents who specified this in their survey return:

[Table 1 about here]

In terms of employment sector, there was a broad spread, with most participants coming from community learning disability teams (14), followed by third sector organisations (10), midwifery services (6), social work (5) and primary care staff (2). This is represented in Figure 1 below:

[Figure 1 about here]

Key informant interviews took place with health staff (6), third sector staff (5) and social workers (2).

### ***Identifying parents and accessing services***

As discussed earlier in this paper, there are a number of challenges associated with identifying parents with intellectual disabilities. In Scotland, official statistics only include those people known to Local Authorities and do not include those people for whom the diagnosis is unclear or those for whom there is no formal diagnosis but an assumption of intellectual disability. In addition, increasingly high eligibility criteria may mean some people are no longer entitled to support and are therefore missing from official statistics. This ambiguity was reflected in responses by survey participants. Those organisations who routinely collected such data supported anywhere between five and 40 parents each year within a single agency. There was broad variation in how the term intellectual disability was understood and this had implications for how this translated into service provision and access to services. Different services had different thresholds for access with some offering support only to those with a diagnosed intellectual disability (predominantly by using an IQ of less than 70 as an indicator of this), while others offered support to those with

*an assumed or suspected learning [intellectual] disability...as most of our parents have never been formally assessed (survey participant 12, third sector organisation).*

Others took a flexible approach and also worked with those with “learning difficulties” or “learning needs”, acknowledging the complexity of circumstances that were likely to affect

these groups. The data suggest that the position of those on the borderline, who do not necessarily have a formal diagnosis of intellectual disability, is uncertain and they appear more likely to present to services in crisis. Statutory health and social work services were clear that they could not work with those whose IQ was above 70, but some respondents, usually those from the third sector, felt that the onus should be on service providers to adapt the support on offer to suit those on the borderline of any diagnostic criteria, regardless of formal diagnosis. Taking a flexible approach appeared to be crucial.

*Even if someone turns out not to have a learning disability, we can't just say if their IQ isn't under 70 we won't work with you.... we have had a couple [of parents] with drink/ drug problems who we are not quite sure about whether they have a learning disability but we would still work with them (Survey participant 27, advocacy worker)*

Applying the theoretical framework described above to the data presented here highlights the unhelpful nature of binary distinctions, as outlined in the care ethics approach, (in this case intellectually disabled/ non intellectually-disabled) in relation to accessing services. Such rigid boundaries mean many parents without a formal diagnosis of intellectual disability, who may benefit from support, often cannot access this. The data suggest that non-statutory, third sector organisations may have greater scope to apply some flexibility and in such cases it appears that the concept of vulnerability was often used to determine need and access to services. There was evidence of some practitioners taking an ethic approach to vulnerability where they equated vulnerability directly with perceived levels of intelligence and capacity:

*Some of the people I work with might not have a formally diagnosed learning disability but they are vulnerable because of their lack of understanding...a lot of girls I work with cannot take in or retain information and they wouldn't be able to concentrate for long enough to read a social work report for example, but they do not necessarily have a formal learning disability (key informant 5, development worker).*

While this has the potential to enable parents to access services (Goodin, 1985), there is a danger in associating vulnerability intrinsically with intellectual disability as it may limit choice and participation and promote negative assumptions about capacity (Fawcett, 2009; Fisher, 2008). Other respondents took an emic perspective where they situated the perceived vulnerability of the parent in its broader social context, acknowledging the broad range of factors that were likely to impact on parenting capacity:

*When you get to know someone, you can tell [if they have an intellectual disability] like the woman I was working with today.... she has had two kids removed as she was targeted by an abusive partner and was thought to be complicit in the abuse of her children... (key informant interview 1, social worker)*

### ***Supporting parents with intellectual disabilities: early intervention***

Accessing services is complicated and is bound up in professionals' understanding of learning disability and vulnerability. This complexity often made it difficult to avoid crisis driven and unplanned interventions even though this was a stated goal of many of the survey participants. A focus on crisis appeared to limit opportunities for strengths or assets

based approaches to be taken and limited the time available for parents to develop their parenting skills. Respondents noted a number of concerns about crisis led interventions and in particular their relationship with child protection issues:

*When inputs are crisis led the focus is more likely to be on child protection and that drowns everything else out...we need to reintroduce more intensive early support*  
(Survey participant, community learning disability nurse)

Despite the challenges involved in promoting early intervention, a number of respondents felt that there was growing awareness of the issues faced by parents with intellectual disabilities amongst professionals as evidenced by an increased number of referrals made at an earlier stage. A number of examples of early intervention were identified such as Early Years Centres which offered support, advice, groups and classes to “vulnerable” families (including those where the parent had an intellectual disability). A key feature of such interventions was the attention paid to the social and environmental factors that might impact on a parent with intellectual disabilities’ ability to parent as well as a specific focus on factors directly related to the intellectual disability, such as the need to work hard to communicate with parents including the provision of information in different formats and repetition of information.

***Supporting parents with learning disabilities: use of mainstream and specialist services***

The complicated picture of service provision revealed a broad range of work undertaken by professionals in this field as evidenced in Table 2 below, which illustrates responses from the 39 participants who completed this question:

[table 2 about here]

The kind of work undertaken suggests that the provision of support often goes beyond the parenting role itself to consider other aspects that might directly or indirectly impact on parenting capacity such as housing support or general health and well-being. This appears to represent an emic understanding of vulnerability that acknowledges the relational aspects of parenting outlined by Fisher and Owen (2008) and goes some way to challenging what they argue is a neo-liberal view that good parenting involves being taught a set of skills by a professional “expert”. While it is important to acknowledge the relational nature of parenting, to deny that many parents with intellectual disabilities will require support from professional “experts” to develop their parenting skills might deny them the opportunity to enhance their parenting capacity.

Survey participants also considered whether mainstream or specialist services might provide the most appropriate support for parents with intellectual disabilities. A complex picture of service provision emerged with services ranging from those only for parents with a diagnosed intellectual disability to those for all vulnerable parents. Other services targeted all people with an intellectual disability therefore the focus was not primarily on parenting. Views on the most appropriate services to support parents with intellectual disabilities were mixed with some respondents believing it took specialist skills and a greater level of

understanding to work with parents with intellectual disabilities. It was clear for example, that mainstream programmes that had not been appropriately adapted (for example to provide accessible information and time for repetition of messages) did not fully meet the needs of parents with intellectual disabilities and respondents valued programmes and services that were flexible enough to meet the needs of parents with intellectual disabilities. Indeed, some respondents felt that support offered by mainstream services would benefit *all* parents who were experiencing challenges with their parenting if they were flexible enough to meet the needs of parents with intellectual disabilities:

*It's more to do with the service rather than the person...the onus should be on the service to meet the needs of the person effectively...they should be flexible enough to adapt accordingly...and some of the things that work for parents with intellectual disabilities will work for everyone...like accessible information is helpful for everyone...a service needs to be equipped to respond to a variety of needs (Key informant 13, health professional).*

Such a response suggests a willingness to move beyond a dichotomous approach towards one that acknowledges that *all* parents might benefit from support with parenting from time to time. This fits well with the ethics of care approach discussed earlier in the paper (Fisher and Tronto, 1990; Tronto, 1993; Sevenhjuison, 2008; Fisher, 2008) that acknowledges interdependence as part of the human condition.

### ***Good practice in supporting parents***

Study respondents were able to identify a number of key features that in their view represented good practice in supporting parents with intellectual disabilities. This included: adapting the pace of parenting programmes to suit the needs of all parents; extending the length of programmes to provide support on a long term basis; repetition of tasks and information; modelling of behaviour; and social support. Parents were also thought to benefit from the provision of accessible information and advocacy support, in line with findings from previous studies (see for example Wade et al, 2007; Llewellyn and McConnell, 2010; MacIntyre and Stewart, 2012). Of particular importance was the need to take a whole family approach that supported parenting capacity in its broadest sense. This involved providing support around housing, health and well-being, finances and social support to access local resources. As one respondent explained:

*There needs to be recognition of the things that might have an impact on parents' capacity to parent...One of the things that services have got involved in is thinking about how other things affect pregnancy – quite often the parent is not in good housing stock, or is not able to manage financially, so it's about supporting parents with those sorts of things, things like applications for housing, budget management... So what we are finding is that services with a primarily clinical focus are straying into all sorts of other areas, it isn't enough to talk about pregnancy, we need to have an understanding of relationships, partner, family, friends, living circumstances, what support they have... (key informant 7, health professional)*

Such an approach requires good joint working between professionals in different organisations and disciplines in partnership with families. Yet study participants reported

significant difficulties in this regard particularly between adult and children social work teams, a consistent area of concern for the majority of participants. It was highlighted that parents with intellectual disabilities often fall between gaps in service provision. Often not eligible for a service in their own right, they fall under the radar until a child protection concern is raised, by which point, the opportunity to focus on the parent's abilities and skills is lost:

*Our local learning [intellectual] disability team are really challenging; the team won't assess the parents whilst they are pregnant...only after the baby is born. Which prevents anything being done in advance, so we are talking permanence planning with babies under six months because we've waited too long to provide a service. The two services work so separately and the two practices don't work well together and there is always a bit of a dispute about who does what and when. (Key informant 12, Social Worker)*

**Discussion: why does inconsistent practice continue despite the growing evidence base?**

This paper contributes to and further develops the growing international evidence base that identifies good practice in supporting parents with intellectual disabilities. We have known for some time that support should take a whole family or family centred approach (Tarleton and Porter, 2012; Wade et al, 2007, Dunst 2002). It should be strengths based and where possible a model of early intervention that avoids crisis-driven working should be adopted. Yet despite this growing recognition of what works, evidence from our study suggests that only pockets of good practice exist, alongside a number of persistent barriers and challenges.

This paper adds to knowledge in this complex area by attempting to explain *why* these discrepancies continue. In order to explain these discrepancies, it is necessary to situate this discussion within the social, political and economic context that influences current practice and debate. It can be argued that there is growing recognition of the rights of people with disabilities, including those with intellectual disabilities, to have a family. This is enshrined in Article 23 of the United Nations Convention on the Rights of Person's with Disability – respect for home and family. Within this article the convention lays out the right of people with disabilities of marriageable age to marry and have children and to decide on the number and spacing of these children. They also have the right to retain their fertility on an equal basis with others (UN, 2006). Practitioners however, must balance promoting this right with the right that children have to be protected from harm. One way would be to adopt a preventative model that prioritises early intervention, while acknowledging that support is likely to be required on a long term basis, particularly at key points of transition (Collings et al, 2017; Stmadova et al, 2017 Stewart, et al, 2016). However, the resource implications of achieving this balance, particularly in times of austerity, are challenging as a result of the introduction of tighter eligibility criteria as a way to ration access to services (Lymbery, 2012). It has been shown here that this has implications for parents with intellectual disabilities, particularly those on the borderline who might find that they are no longer entitled to a service. This is likely to promote a crisis driven rather than a preventative model of practice.

While this goes some way to explaining the barriers that currently exist in supporting parents with intellectual disabilities, it does not fully explain the variations in practice

identified in this paper. In order to make sense of this it is necessary to understand the varying ways that professionals appear to have constructed and understood the concept of vulnerability. The findings outlined above evidence two different ways of constructing vulnerability with some respondents seeing this as something inextricably linked with intelligence and levels of understanding (in line with an etic approach). Others took a broader (emic) approach that considered the experience of the individual within their broader social context (Speirs, 2008). This involved looking beyond the intellectual disability and recognising that this alone did not determine a parent's capacity to parent. Rather, parenting capacity was likely to be influenced by (for example) living in poor housing or experiencing domestic abuse. Nonetheless, whichever approach to constructing vulnerability that professionals took, they all used this as a way to justify or determine access to services. This leads to a further tension or dilemma for professionals working with parents with intellectual disabilities. While being viewed as vulnerable is necessary to access support it raises doubts around capacity to parent. Parents labelled in this way are likely to experience stigma and discrimination that may have a direct impact on their ability to parent. Kittay (2011) in her discussion of care suggests that in a world where independence is viewed as the norm, those who need care are stigmatised. The same argument can be applied to those who need support in order to parent their children. Fisher and Owen (2012) draw on the work of Honneth (2001; 2003) and his concept of social recognition to suggest that a high degree of emotional work is required to repair identities that have been spoiled (Goffman, 1963) due to a lack of recognition in both the public and private spheres. Parents with intellectual disabilities who often have their right to parent questioned and their capacity to parent challenged are likely to experience this misrecognition on a regular basis. Like other marginalised groups of parents, it can be

argued that they are often “discursively positioned outside the boundaries of normal motherhood, commonly seen as victims or as threats to the moral order” (McDermott and Graham, 2005: 59).

The work of Parton (2003) helps make sense of the different ways in which professionals might deal with these challenges. Writing about social work, he challenges the view that social work is always a caring profession, arguing that social workers are often complicit in maintaining, or at least not challenging, the conditions that lead to powerlessness and marginalisation of groups such as parents with intellectual disabilities. He attributes this to the rise of managerialism and argues that an ethic of care approach can help to counter-balance this. He argues that social workers are often conflicted between their own priorities to empower and support service users to achieve their goals and the priorities of their organisations around legal obligations, performance indicators and so on. Parton (2003) argues that an ethics of care approach helps avoid taking a top-down approach where professionals simply follow the rules encouraging a shift towards greater reflexivity which encourages professionals to enter into a dialogue with service users to clarify what support might be needed while recognising that there might be differing views of what a successful outcome might be. Adopting such an approach would involve giving recognition (or value) to the lived experience, knowledge and expertise that marginalised parents with intellectual disabilities bring from their experience of the private and public sphere thus equalising power relations to some extent (Fisher and Owen, 2012). Parton (2003) argues that this calls into question more traditional bureaucratic approaches of support provision. It involves not only being more democratic but adopting a stance of “not knowing” and not being the “expert” on the “problem”.

Parton's argument chimes with Fisher and Owen's (2008) who distinguish between economies of performance and ecologies of practice, drawing on the work of Stronach et al (2002). Economies of performance relate to the managerialist, rule based practice discussed by Parton (2003). This is dominant in public service contexts and is best exemplified in performance measures, standardised staff and service user assessments and protocols, many of which featured in the accounts given by participants in our study. Ecologies of practice on the other hand bring together individual and collective experiences including classroom based or theoretical knowledge, work based knowledge and personal commitment to particular practices. Ecologies of practice often include what Gleeson and Knight (2008) refer to as 'underground working', in other words 'going above and beyond' what is expected, working flexibly and beyond the formal job description to offer additional support to service users. The findings from our study provided examples of both forms of practice and it is likely that the areas of good practice identified above often depended on staff who were willing to 'bend the rules', those who were likely to have a personal commitment to supporting families where one or both parents had an intellectual disability.

### **Recommendations for practice**

Such a commitment to supporting families is likely to involve working in partnership, not only with other professionals but with parents with intellectual disabilities (as outlined by Spencer and Llewellyn, 2007), recognising the expertise that all parties bring to this relationship. We therefore recommend enhanced partnership working that takes a family-centred, or whole family approach. This will help to ensure that families where one or both

parents have an intellectual disability do not fall in the gap between children and adult services, which often results in the needs of parents being overlooked.

This approach must acknowledge the expertise that parents and children have about their own lives and support needs. This involves a shift in attitudes and requires professionals to concede their “expert” status (Parton, 2003) to recognise and value different types of knowledge and expertise. To support this process, we recommend the introduction of training at qualifying level for social work and nursing students to raise awareness of the particular issues faced by families where one or both parents has an intellectual disability, while acknowledging the similarities with other groups of potentially “vulnerable” families. These messages must be reinforced at post-qualifying level by offering more experienced practitioners greater opportunity to reflect on their practice and to learn from the first hand accounts of parents with intellectual disabilities (authors, 2016).

## **Conclusion**

Understanding the different types of practice outlined above helps us to make sense of the persistent challenges and barriers that remain in supporting parents with intellectual disabilities. In order to overcome these challenges, it is necessary to view the experiences of parents with intellectual disabilities in the same way as other parents who might experience periods of vulnerability. While it is undeniable that parents with intellectual disabilities are likely to need additional support to parent, often on a long term basis, this paper has provided evidence from a national study in Scotland to argue that the kind of support required would benefit other families who might experience difficulties or

vulnerabilities in their life from time to time, not only those with intellectual disabilities. By acknowledging the relational and interdependent nature of family life, in line with an ethics of care approach, it is accepted that everyone has the potential to be vulnerable and hence require support, at different points in the life-course. By accepting this, support to parent would become the norm and would not be used to discriminate against certain groups of parents, as in a recent court judgment in England where the support received by a parent with intellectual disabilities was viewed as tantamount to substituted parenting and therefore used as evidence of the parent's lack of capacity to parent (Local Authority V A, 2017). Normalising the support needs of parents with intellectual disability would reduce the negative impact and stigma of being labelled as vulnerable and might result in conditions more conducive to adopting a whole family approach.

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