

**TITLE:** “*She was there if I needed to talk or to try and get my point across*”:  
Specialist advocacy for parents with intellectual disability in the Australian child  
protection system

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## Introduction

Adults with intellectual disability who express a wish to become parents can face considerable opposition from within their social networks and, if they become pregnant, may be pressured to end the pregnancy by family members (Mayes, Llewellyn, & McConnell, 2006) and social workers (Booth & Booth, 1995). Those who have children live in fear of having them taken away (Booth & Booth, 2004; Llewellyn & McConnell, 2010; Mayes, Llewellyn, & McConnell, 2008). According to child protection prevalence studies, these fears are well founded. Parents with intellectual disability are at higher risk of coming to the attention of child protection authorities and of having their children permanently removed (Booth, McConnell, & Booth, 2005; Feldman, McConnell, & Aunos, 2012; Llewellyn, McConnell & Ferronato 2003; Taylor et al., 1991). This overrepresentation has been attributed to a number of compounding factors including multiply disadvantaged backgrounds characterised by childhood adversity, low educational attainment and social isolation (Cleaver & Nicholson, 2007; McConnell et al., 2011); parenting in precarious conditions with greater exposure to poverty, family and intimate partner violence; and high levels of stress, all of which are known to detrimentally impact on parental emotional and physical health (Aunos & Feldman, 2002; Belksy, 1984; Cleaver & Nicholson, 2007; Emerson & Brigham, 2014; McConnell et al., 2011).

Entrenched assumptions by professionals and the community at large about the capacity of persons with intellectual disability to raise a child result in these families facing greater scrutiny and heightened perceptions of risk to children by the practitioners they encounter (Collings & Llewellyn, 2012; Lewis, Stenfert-Kroese, & O'Brien, 2015; Proctor & Azar, 2013). Once under the gaze of social services and child protection authorities, the compounding effects of prejudicial assumptions and

discriminatory treatment (McConnell & Llewellyn, 2000; Tarleton et al., 2006), inappropriate or inadequate service support (Booth & Booth, 2005; Tarleton, 2008), and unrealistically high expectations by caseworkers of what constitutes ‘good enough’ parenting (Cox et al., 2015) set these parents up to fail (McConnell & Sigurjonsdottir, 2010; Sigurjonsdottir & Rice, 2017). Indeed, the systematically differential treatment of parents with intellectual disability in child protection matters has been described as “institutional abuse” (Tarleton, 2008, p 135).

Unquestionably, protecting children’s right to safety and stability must be the paramount concern in care proceedings. Article 3 of the Convention on the Rights of the Child (United Nations General Assembly, 1989) states that the “best interests of the child shall be the primary consideration” in all actions concerning children. Article 9, on the legal separation of children from parents, states that all interested parties have a right to “participate in the proceedings and make their views known” (para. 2). When the interested party is a parent with intellectual disability, a case can also be made under the Convention on the Rights of the Persons with Disabilities (CRPD) (United Nations, 2006), that additional support will likely be needed for them to exercise legal capacity to participate in proceedings and have their views heard.

According to Article 12 of the CRPD, achieving equal recognition before the law may require states to take “appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (para. 3). Article 13 calls for the provision of procedural accommodations to ensure people with disability have access to justice “on an equal basis with others” (para. 1) and that “those working in the field of administration of justice” receive appropriate training (para. 2). There is now a compelling body of evidence that parents with

intellectual disability fare poorly in their encounters with child protection authorities and courts in ways that are directly attributable to assumptions about their impairment, and that the absence of legal and procedural accommodations continues to have serious consequences for the lives of these parents and their children.

In Australia, parents facing care proceedings who are assessed as being low income, a test that most parents with intellectual disability would meet, are assigned a publicly funded lawyer (known as Legal Aid). This generalist legal practitioner typically carries a high caseload, limiting their capacity to take the extra time that clients with intellectual disability may need. In any case, these lawyers may lack the specific disability knowledge and communication skills to explain processes in ways that parents with intellectual disability can understand. In the New South Wales (NSW) jurisdiction, where this study took place, there is provision for a *guardian ad litem* to be appointed if a parent is deemed unable, by virtue of their cognitive capacity, to give legal instruction. This practice is commonly granted by magistrates on the recommendation of a lawyer and without any independent and expert assessment of the parent's legal capacity (Flynn, 2015).

Care proceedings take place in stages, warranting repeated court appearances before a matter may even be heard and with frequent adjournments on procedural grounds. Between hearing dates, parents are expected to attend meetings where people talk about them or at them and spend far too little time listening to their views (Tarleton, Ward, & Howarth, 2006). Parents are also called on to meet with child protection caseworkers and managers, and are frequently interviewed without the support of their lawyers or an advocate (Booth & Booth, 2004; Tarleton, 2007). Parents have reported feeling intimidated, having words put in their mouths, and

feeling like a spectator in the process at these meetings (McConnell & Sigurjonsdottir, 2010). Research reports that parents are often surprised, and feel further betrayed, when what they thought was an informal conversation with their child protection worker is subsequently presented to the court (Douglas & Walsh, 2009).

In an effort to demonstrate willingness to do whatever it takes to get their children back, parents with intellectual disability will often agree to undergo parenting capacity assessments, that are frequently undertaken by clinicians lacking professional expertise in intellectual disability or who are not abreast of the latest evidence pertaining to parents with intellectual disability and their children (Cox et al., 2015). Parents with intellectual disability are also often subject to psychometric testing and assessment methods which may be used inaccurately and/or inappropriately to make broad claims about their parenting capacity (Spencer, 2000). Research indicates that parents with intellectual disability exit the legal process feeling that they have been treated unjustly, complicating their ability to come to terms with their loss and compounding a pervasive sense of powerlessness (Gould & Dodd, 2008; Mayes & Llewellyn, 2012) and confusion (Booth & Booth, 2005; Conder, Mirfin-Veitch, & Sanders, 2008), which often persist long after their children have been removed.

Previous Australian research reported on the serial nature of grief for many mothers with intellectual disability who had multiple children removed (Mayes & Llewellyn, 2012) and a United Kingdom (UK) study found that the profound trauma caused by the loss of a child led to a deterioration in physical and mental health, sometimes culminating in suicide attempts (Gould & Dodd, 2014). Mothers in this study said they felt unable to express their grief for fear of negative repercussions or a lack of trust in counseling.

Over a decade ago, Booth and colleagues (2006) warned that parents with intellectual disability in the UK faced ‘temporal discrimination’ in a child protection system that failed to allow them time and support to overcome parenting obstacles. More recently, Cox and colleagues (2015) argued that streamlined court procedures designed to improve timely decision-making in the interests of children may inadvertently discriminate against these parents who need more time and support to access justice on an equal footing with others. Similar moves are currently afoot in Australia, where the ‘drift’ into out-of-home care (OOHC) within the general population has seen numbers spike at 40,000 in 2017, nearly half of this in NSW (AIHW, 2017). Among the policy remedies to address this dramatic rise is a reduction in the time taken to reach a final placement decision through improved permanency planning and more explicit timeframes for restoration efforts (Ross & Cashmore, 2016; Tilbury & Osmond, 2006). Based on the earlier evidence, there is a risk of judicial expediency which, for parents with intellectual disability, may further reduce their ability to obtain equal justice before the law.

Advocacy is an established mechanism for ensuring vulnerable groups have equal access to justice (Flynn, 2015). Advice and advocacy has been shown to increase the capacity of parents to participate in care matters (Lindley, Richards & Freeman, 2001) and to work in partnership with child protection services (Featherstone, Fraser, Ashley & Ledward, 2011). In the UK and Ireland, there is a precedent for the provision of specialist, independent advocacy during child protection proceedings as a mechanism to correct the power imbalance between a parent with intellectual disability and the range of professionals they encounter (Booth & Booth, 2005; Flynn, 2015; Gould & Dodd, 2014; Tarleton, 2007; Ward, 2010). However, despite policy commitments in this area, such advocacy is still not

widely available (Featherstone et al., 2011; Ward, 2010). To date, there is no research about the effectiveness of advocacy in improving access to justice for parents in the child protection system in Australia, nor research that specifically explores the experiences of parents with intellectual disability who receive advocacy support. Indeed, to our knowledge, the only specialist advocacy program for parents with intellectual disability facing care proceedings in Australia is based in NSW.

It has been argued that practice developments in child protection have relied on research informed largely by the perspectives of professionals (Smithson & Gilbert, 2017). Some have argued that it is important to take parents' experiences of child protection into account in order to improve practice (Tilbury et al., 2010). Mothers involved in the child protection system have been described as being "written out of history, ghosts to us, their voices lost" (McGhee & Waterhouse, 2017 p 1653). McGhee and Waterhouse (2017) analysed the speech acts of mothers involved in the child protection system in Scotland to reveal literal and symbolic expressions of dispossession and theft in their accounts. Given their overrepresentation in child protection and the barriers they encounter in exercising their legal rights, it is essential that the voices of parents with intellectual disability are heard. This study explores the views of parents with intellectual disability who received independent advocacy during care proceedings in NSW. Given the range of reforms underway to child protection in this Australian state (Tune, 2016), the results offer a timely opportunity to inform emerging statutory and legal practices.

## **Method**

The study explored the role of independent advocacy offered by a specialist program for parents with intellectual disability involved in care and protection matters. The

program was based at the Intellectual Disability Rights Service (IDRS), a community legal centre that supports people with intellectual disability in the justice system. The program consisted of a paid advocate, a specialist child protection lawyer, and a small number of volunteer advocates who provided court support. The advocacy role included liaison with child protection, court, hospital and other professionals on behalf of the parent, attending case meetings, and assisting parents to access public housing and social benefits. The study involved qualitative accounts from parents, paid staff, and volunteers about their involvement in the program and a case file review, the results of which are reported elsewhere (Collings, Dew, Gordon, Spencer & Dowse, 2017). This paper reports solely on the perspectives of parents about the support provided by the paid advocate. The study was approved by the Human Ethics Research Committee (UNSW Human Research Ethics Committee (HC 16559)).

## **Recruitment**

A convenience sample of parents was recruited by IDRS and were current or past users of a program it operates for parents with intellectual disability involved in child protection proceedings. Parents who accessed the program were not required to have a formal diagnosis of intellectual disability or to have an IQ assessment. Referrals came from parents who identified with a label of intellectual disability, as well as their family members and service providers who worked with them. This approach is consistent with the social systems definition of intellectual disability developed by Mercer (1973), commonly used by researchers to ensure parents with mild or borderline disability are not inadvertently excluded from research. Given that these parents had experienced the emotional turmoil of involvement in the child protection system and some had lost custody of their children, the advocate, who worked closely

with all parents, was best placed to identify suitable participants and could offer parents an impartial perspective on the potential benefits or risks of participation in the study. The advocate approached only those parents whom she believed would be likely to have an interest in sharing their views and were not currently experiencing high levels of distress. Potential participants were invited to participate and the advocate used a purpose-designed research script to provide them with information about the study. An information and consent protocol was read aloud to parents who expressed an interest in the project to ensure informed consent was obtained [all study materials available from the first author upon request]. A suitable time and venue was then arranged for the parents to take part in an interview.

### **Participants**

Seven mothers and three fathers agreed to be interviewed. Parents were invited to bring a support person along to the interview and four did so. Two support people were family members, one being a partner (and child's father) and another a participant's mother, and the remaining two were the advocate and a program volunteer. Parents were aged between 19 years and early 40s and lived in metropolitan and regional areas of NSW, Australia; seven lived with a partner, two with parents or in-laws [one person lived with a partner and a parent], and two alone. Parents had up to four children (Mean = 2). Eight parents had a child in foster or kinship care. Participant details are provided in Table 1. Pseudonyms are used to preserve parents' anonymity.

*<Insert table 1 about here>*

## **Procedure**

A qualitative approach involving semi-structured interviews was used to explore how the parents perceived the support they received through the program, particularly from the paid advocate. Individual interviews for eight parents took place at their family home or the regional offices of IDRS. Two parents living outside Sydney were interviewed by telephone. The first author conducted all interviews, which were, on average, 60 minutes in duration. Interviews were digitally recorded and transcribed with identifying details removed. Parents were not explicitly asked about the child protection matters in which they were involved; however, over the course of the interview, most parents shared personal stories about their background, children, and the circumstances surrounding their child protection matters.

## **Data analysis**

An inductive thematic analysis approach was used to develop themes (Braun & Clarke, 2012). De-identified interview transcripts were imported into NVivo11™, a qualitative data management software program. Corroboration from more than one researcher was utilised to maximise confidence in the validity of themes (Gibbs, 2007) and so data were independently coded by the first and third authors through close reading of each transcript, with codes assigned to each line of data. Codes were then grouped in broader categories. Data saturation was reached when no new codes were identified. Categories were confirmed through discussion between the two researchers who then reached agreement on themes and sub-themes. Figure 1 depicts the coding process used to generate the theme ‘making a difference’. Three main themes were identified: 1. Powerlessness; 2. Dealing with trauma; and 3. Making a difference.

<insert Figure 1 about here>

## **Results**

The themes related to how the parents viewed having an advocate during their contact with the child protection system. The first two themes addressed the need for advocacy due to the feelings of powerlessness parents experienced in child protection and court systems, and dealing with the trauma of child removal and encounters with the child protection process. The third theme related to the positive difference advocacy made in the lives of the parents, from fostering understanding of the legal process to the acquisition of skills and confidence and feeling valued as a person.

Table 2 outlines the themes and subthemes.

<insert table 2 about here>

### **1. Powerlessness**

A sense of powerlessness was a fundamental feature of the lives of all parents. Parents reported feeling that the child protection and justice systems had all the power and that they personally lacked control or agency. Four sub-themes describe the sense of powerlessness: i) bewildering process, ii) not being heard, iii) assumption of incompetence, and iv) blaming the victim.

#### ***Bewildering process***

Participants described the justice system, which included police, courts, and lawyers, as confusing and inaccessible in terms of information and the language used. Sophia stated “*court is really hard because you don't know what to expect*” and Troy echoed this sentiment, saying, “*I don't understand what the judges are saying*”. A common experience reported by parents was confusion about what changes they were expected

to make in order to have their children restored. Vince felt that Child Protection Authority (CPA)<sup>1</sup> kept changing the goalposts saying, “*we obeyed every commandment they told us to do but they were lecturing us that we're not looking after our kids*”.

Participants reported feeling constant and often contradictory demands to prove themselves as capable to parent their children and many showed considerable resilience in this regard. Mandy explained that CPA staff had not only continually criticised her parenting but often contradicted each other:

*When they still come to our home we feel like we're doing things that are wrong. You think you're doing the right thing and to them it's the wrong thing. The wrong thing turns out to be the right thing. We enrolled (daughter) into (child care) because they said she needs that early childhood development then DOCS said, 'She's too young. She should be at home'. We were so confused.*

### ***Not being heard***

All parents described contact with CPA in negative terms and there was a perception that workers were out to undermine them and collude with the justice system to deny them parenting rights. Parents commonly observed that CPA and court staff did not listen to them. As Nick said, “*no-one was listening to what I was saying*”. The feeling of being overlooked was not only disempowering for parents but also a source of frustration. Sophia summed this up saying, “*I wish they would listen to one person: me*”. The fact that Nick was denied the mandatory support available to people with

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<sup>1</sup> Refers to the State Government Department which has legislated responsibility for child protection in NSW.

intellectual disability when being questioned by police exemplified the extent to which the justice system lacked disability awareness. As he explained, *“I told them (the police) I had an intellectual disability, but they never asked me if I needed any support people or anything”*.

### ***Assumptions of incompetence***

Parents’ engagement with the child protection and court system reinforced a lifelong sense of being devalued because of their intellectual disability. Their accounts of everyday life revealed the routine assumptions of incompetence they faced and encounters with systems that appeared to have pre-judged their fitness to parent. As Beccy put it *“They were using the fact that I had an intellectual disability and said I needed a cognitive report done to see how it affects my parenting”*. Alexis, whose child was born with complex medical issues, felt that she was not given a chance to show she could be a good parent, saying *“They said because of my intellectual disability I would not be able to take care of a special needs child”*.

### ***Blaming the victim***

Five of the seven mothers who took part in the study had experienced domestic or family violence at the hands of their child’s father. Rather than feeling supported to address the complex issues associated with their family violence situations, or to deal with their own trauma-related issues, they felt judged by CPA workers because their children had been exposed to violence. As Nicole explained, *“I wasn’t allowed to have contact with my daughter’s father because I have an AVO [apprehended violence order] against him (but) I did (because) I felt sorry for him”*. As a result of this breach of the AVO, Nicole’s child was removed. Two mothers were physically assaulted by their partner during the pregnancy with Sophia saying, *“He almost killed me. He nearly put my bone here into my brain”* and Jessica explaining, *“I hid my*

*pregnancy because I was in a domestic violence relationship*". When hospital staff became aware of the domestic violence Jessica had experienced, her newborn was removed. Similarly, Beccy, whose newborn was removed due to her partner's violence said that, *"he's no longer in the picture at all so I'm wanting ...to see if (child) can actually come home"*.

All these mothers felt they had been doubly victimised. Not only were they subjected to violence but they were then punished by having their children removed. Having survived abusive relationships, they felt they were held responsible by CPA and courts for making bad relationship decisions. While the system rightly prioritises the safety of children, none of these mothers felt they had received information or support that would have helped them leave the violent relationship. In some cases, the advocate helped the mothers to recognise and accept the abusive nature of their relationship, and linked them into domestic violence awareness courses and counseling.

## **2. Dealing with trauma**

Another key theme was the traumatic nature of the child protection process for parents and the emotional toll of this experience. Two sub-themes describe the experience of dealing with trauma: i) grief and despair following the removal of their child, and ii) inadequate informal support to help them through the experience.

### ***Grief and despair***

All of the parents had experienced the emotional toll of forcible separation from their children. Five children were permanently placed in out of home care and two in kinship care. Two fathers had been required to move out of the family home during the child protection investigation; Troy's matter was on-going and Nick had since

been reunited with his family. Only Mandy had her child restored following an investigation but still described her engagement with the child protection system as traumatic, explaining, *“It was so stressful ... and it put a lot of pressure on us”*.

All four mothers whose infants were removed shortly after birth described the experience in terms reminiscent of a theft, with Sophia saying, *“they came to the hospital and just took her”*. Mandy recounted the shock of the encounter saying, *“we were just about to go home and (CPA workers) came and straight away removed her”* and Jessica expressed dismay that, *“they didn't even let me see her”*.

In addition to the grief and loss of having a child removed, half of parents reported mental ill-health including anxiety, panic attacks, agrophobia, depression, suicidal thoughts, and post-traumatic stress related to their encounter with the child protection system. Sophia described the anguish of losing her child who *“symbolises something in my life that I have succeeded in. The only thing I've ever wanted”*. Marion said, *“it's really hard for me not to see my kids (and) very sad and depressing when they leave. My kids are having a good life but I want to be in their lives”*. Jessica explained that when her child, who now lives with her mother, says *“Mama, I want to live with you”, it's very emotional when I hear that”*.

Three parents explicitly stated that they contemplated suicide. Nick said, *“There was times there where I just felt like I wanted to neck myself”* and Troy echoed this, saying *“I just want to end my life. Just so the pain will go away”*. Two of these parents noted that they contacted the advocate when they were at their lowest and she had provided crucial emotional support. Marion explained, *“I just felt suicidal, so I just rang her (advocate) up and told her”*.

### ***Inadequate informal support***

Four of the ten parents lacked any reliable and helpful support from family or friends and these individuals were most at risk of ongoing mental health issues. Marion said, *“I’ve got my family but they’re not supportive. I’ve got friends but they’ve got problems as well so I just try and keep to myself”*. Sophia, who herself had been in OOHC as a child stated, *“I’ve had a real bad background. My mum lost all us kids”*. She went on to explain that ongoing abuse throughout her life had left her unable to trust people. *“Because of what people have done to me I don’t like people. That’s why it’s very hard [for] me to make friends”*. Social isolation not only left her and other parents devoid of assistance during the child protection process but lacking the informal support that courts took into account when recommending placement options for the child. In terms of kinship, Vince was fearful that his children would be placed in the care of his partner’s family, despite a history of family violence. As he explained, his partner had *“been beaten up by her stepdad and I don’t want (him) to have contact”*.

Even those parents who had supportive family and friends sometimes preferred not to talk about what they were going through. Troy explained that, *“I’ve got heaps of mates. It’s something that I don’t want to talk to them about. I don’t want them to worry about me”*. He also worried that his situation was having an impact on the fragile health of his father. Vince had sought help from his siblings but explained that, *“they haven’t had time because they’ve got their own kids. They’ve got their own problems”*.

### 3. Making a difference

This theme conveys the multi-faceted nature of the [name removed for blind review] advocacy role and its impact on the lives of the parents. There are three sub-themes: i) building a bridge between the parent and the child protection and court systems to foster improved communication and disability awareness; ii) building parenting skills and confidence; and iii) valuing parents as people.

#### *Building a bridge*

Within the judicial system, the parents saw the advocate as an intermediary between themselves, lawyers and courts. She was the person who translated complex legalese into simple language or, as Mandy put it, “*she broke it down for me so I could understand*”. Notwithstanding an onus on courts to ensure that all parents facing child protection matters have the legal process explained to them, parents with intellectual disability face an additional barrier to understanding posed by their learning difficulties. Marion explained, “*She gave me real support through court to get me to understand the paperwork*”. The parents felt that the advocate made sure other professionals took their disability into account. As Beccy put it, “*She says what rights I have, and what I should get because I have a disability*”. Having someone who took the time to explain what was happening in language they could understand, and who insisted that lawyers did the same, meant that the parents were able to participate more equally in a difficult process. This is summed up by Troy who said, “*when I got mixed up with questions she was there to help me explain what they were saying*”.

Parents also referred to the extensive advocacy they received in their dealings with child protection and other agencies, in which the advocate “*assisted with everything (to do) with [CPA] and with my appointments*” (Jessica). The advocate

routinely attended case plan meetings with parents, made phone calls on their behalf, helped them to access parenting and other courses recommended by CPA, and liaised with hospitals, and other government agencies around housing and welfare payments.

### ***Building parent's skills and confidence***

All the parents reported that the advocate had not only provided critical liaison with CPA and other government departments and courts but had also helped them gain skills and confidence by explaining what was happening in a manner they understood, and facilitating their access to appropriate training and support. As Jessica explained, *“I don't really understand just by talk, I have to do with action and with picture. She (advocate) went into the hospital and educated them about a person with an intellectual disability”*.

For the mothers who came under child protection scrutiny immediately after the birth of their baby, the advocate worked closely with hospital staff so they could understand and respond appropriately to the mother in order to develop her parenting skills. The advocate also liaised with CPA workers to ascertain what concerns they had for the infant's safety, and then provided evidence about the informal support available to the new mother, thus providing an alternative to removal. As Jessica, whose first child was placed in the care of her mother and who then received the pre-natal advocacy that enabled her to retain care of her newborn, put it, *“I said to my mum: If I had this support before I would still have (my first child) with me”*.

But more than simply being just another professional who spoke for and about the parents in encounters with yet more professionals, the advocate was a reassuring presence for the parents that helped build their self-confidence. Vince explained that, *“She looks so confident and (that) makes me confident. I feel unlocked. I feel safe (so)*

*I can speak my words for once*". Alexis talked of the advocate helping him to communicate his views more effectively, saying, "*She was there if I needed to talk or to try and get my point across*". Gaining self-confidence also helped parents to see themselves as capable of dealing with future life challenges. Nicole, who lived with her child in a kinship care arrangement with her birth family, described becoming stronger and more able to see herself positively after feeling she had failed in so many aspects of her life previously. As she put it, "*I used to give up on everything (but) I'm not going to give up. This is my daughter*".

### ***Valuing the person***

The parents universally reported having a positive connection, or as Nicole put it, "*a good bond*" with the advocate. They felt they could rely on her to be honest and emotionally available when they needed her. As Mandy put it, "*I could text her about anything, not just for the legal matter*". For many parents, this was an unfamiliar experience. As Beccy summed up, "*It's actually nice that somebody actually cares. I've never had that*". Several parents described the relationship as "*like a friendship*". Attempting to convey how important the advocate was to him, Nick explained that, "*it was like we became sort of friends*" and Alexis said that the advocate had "*become a good family friend*".

The parents described the relief of knowing they could express themselves openly with the advocate. Most had not felt able to share their thoughts, fears, and emotions with professionals or family members in the past. As noted earlier, many had lacked positive role models for interpersonal relationships or were quite isolated. An ongoing relationship with the advocate gave parents' permission to express difficult emotions without fear of judgment or rejection. In the words of Sophia, the advocate "*knows me that well now that when I do get stressed, she knows*". Feeling

personally cared about provided important emotional benefits for parents. Several parents reported that the advocate seemed to know what to say when they were feeling low. As Troy put it, “*she does care about me. She lifts me up a bit*”.

## **Discussion**

The results confirm earlier studies about the powerlessness experienced by parents with intellectual disability in their involvement with child protection authorities and courts. Previous research has found that parents are overwhelmed and confused by the child protection process (Booth & Booth, 2005; Conder, Mirfin-Veitch, & Sanders, 2008; Tarleton, 2007; Tarleton et al., 2006). Parents in this study reported that they found the child protection process bewildering and felt that they were not listened to by CPA workers, lawyers and judges. McConnell and Sigurjonsdottir (2010) similarly reported that parents experienced a sense that they were spectators to the child protection process, with little influence over the outcome.

The results echo earlier research from Australia and elsewhere which reported that parents face ongoing trauma following child removal (Gould & Dodd, 2014), which can be serial in nature (Mayes & Llewellyn, 2012). The parents in this study also shared accounts of grief about the loss of their child and their primary role as a parent. Mothers whose newborns were removed from hospital expressed this as a theft, echoing earlier research with a non-disabled group of mothers involved in child welfare (McGhee & Waterhouse, 2017). Coupled with insufficient contact, particularly for those with children in foster care, many of the parents were at risk of suicide and ongoing mental ill-health. This points to an urgent need for the provision of specialist mental health support and counseling for parents with intellectual disability at the time of their child’s removal.

The effects of often lifelong disability-related discrimination and stigma had left many parents with a legacy of low self-esteem and a pervasive sense of fatalism and failure. It is no small achievement for the advocate to have built such trust with these parents given their mistrust of services and professionals, the traumatic circumstances of their involvement with the service, and the probable permanent removal of their children. The findings in this study suggest that, apart from providing practical support, advocacy offered a relationship model based on reliability, respect and affirmation, which increased parents' capacity for self-determination. This extends earlier research about the role of an independent advocate for parents with intellectual disability facing care proceedings (Flynn, 2015; Tarleton, 2007; Ward, 2010) by showing that, from the parents' perspective, having a trusting relationship with an advocate who values them as a person, also helped build self-confidence. In light of a history of trauma, abuse, and bullying experienced by most parents in this study, the finding suggests that parents with intellectual disability can be very receptive to timely, appropriate and sensitive support. As a form of support, advocacy offers the potential to assist parents to build their own capacity for self-advocacy.

The results in this study show that the practical and emotional support from a specialist disability advocate helped parents to understand the child protection process and to cope with the requirements placed on them to attend case plan meetings and court hearings. This is consistent with earlier findings in the UK (Featherstone et al., 2011; Tarleton et al., 2006, Tarleton, 2007; Ward, 2010). This support may be particularly critical for parents who lack reliable informal networks but, as the results suggest, is needed irrespective of whether a parent with intellectual disability has access to adequate informal support or not. While the risk of mental illness and

suicide is likely to be higher for parents who are socially isolated, even parents who have access to reliable, positive support from family and friends experienced confusion and despair during their encounters with the child protection system.

The findings in this study reinforce earlier research that indicates parents with intellectual disability are blamed for the failures of services to adequately support them (Booth & Booth, 2005; McConnell & Llewellyn, 2000). In one case, the advocate was able to build a bridge between the parent and hospital staff to facilitate appropriate infant care training and foster hospital staff disability awareness for a mother who would otherwise have had a second child removed. This underlines the importance of independent, early assistance during pregnancy to support a parent's learning.

The emotional toll of child protection involvement was magnified for most parents by a history of domestic violence, childhood adversity, ostracism and bullying. This study provides an update to the extant literature about the shadow of violence and abuse in the lives of mothers with intellectual disability and their children (Booth & Booth, 2004; Cleaver & Nicholson, 2007; Collings & Llewellyn, 2012; McConnell et al., 2011). The majority of women connected with the study, including female participants and the female partners of male participants, had experienced family and/or intimate partner violence. Three mothers had newborns removed at hospital due to the risk posed by the child's father who had a history of violence or sex offending, and partner violence was a factor in the removal of two older children. A systemic response exclusively targeted toward protecting children from harm left these women feeling punished rather than protected from male violence.

In reflecting on earlier work by McConnell and Llewellyn (2000, 2002), the results in this study suggest that little has improved in relation to the deeply held negative assumptions of child protection workers and courts about these parents. For parents with intellectual disability involved in child protection proceedings, their encounters with CPA workers and court professionals often reinforce negative attitudes about their competency. The parents in this study felt judged as unfit parents without being given the opportunity to prove themselves. Once their matter was before the court, their interactions with legal professionals left them feeling unheard and overlooked.

Parents who are involved with the child protection system find this experience confronting and distressing. For parents with intellectual disability, this is magnified by the difficulties they face in being understood and in understanding and participating in the process. There is growing recognition within the judiciary of the need for judicial processes to be responsive to the particular issues of vulnerable groups who come before the court. Therapeutic jurisprudence looks at the impact of law on people's lives and calls on us to think creatively about how legal process can be reshaped so as to "avoid imposing anti-therapeutic consequences whenever possible" (Winnick, 2009, p 540). It is evident that encounters with the child protection process further traumatizes these already vulnerable parents. Advocacy has been shown to be an effective accommodation that facilitates parents' equality before the law. Moreover, as demonstrated by these findings, it can serve as a point of validation and buffer against the emotional impact of losing one's child into care.

Despite consistent research findings and repeated calls in the UK, Ireland and now Australia for all parents with intellectual disability to have access to advocacy throughout an investigation, recognition and support within the child protection

process to address this need is yet to be developed. This lack of support potentially also places child protection systems in breach of obligations under the CRPD (2006).

### **Limitations**

The results are based on a small, qualitative study conducted in NSW, Australia and reflect the experiences of a small number of parents with intellectual disability. The study recruited only parents who had been engaged with a single specialist program that operated in a limited geographical area of that state. It is possible that these results may not reflect the broader experiences of parents with intellectual disability in NSW. Given that care and protection matters are investigated by the state government and heard by local Children's Courts, it is possible that different child protection and court practices occur in other Australian states.

### **Conclusion**

Parents with intellectual disability require specialist support when they come into contact with the child protection system. This should include advocacy support in their dealings with child protection authorities and others during an investigation and support at court. This service is an essential adjustment to address the power imbalance between these parents and the professionals they encounter. This is a disability-related accommodation, both as it impacts on their capacity to understand the process and advocate for themselves, and by virtue of the pejorative assumptions made about them because of their disability. Advocacy not only redresses inequalities for this group of parents and helps to build the skills and capacity of parents with intellectual disability, but also has the potential to improve disability awareness in professionals and institutions and inclusion for people with intellectual disability facing court, more generally. To achieve this end, the provision of specialist,

individual support for all parents with intellectual disability in care proceedings is consistent with the obligations required by signatories to the CRPD (United Nations General Assembly, 2006). Enabling a more equitable and effective child protection system will result in better individual, family and community outcomes.

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