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Title: If we know what works, why aren't we doing it?

Running Heading: A critical commentary on the 'problem' of achieving social justice for parents with learning disability and their children.

Abstract

High rates of child removal from parents with learning disabilities persist despite substantial evidence that parents with learning disabilities can provide their children with satisfactory care given appropriate support. Child welfare interventions disproportionality based on disability status presents a compelling social issue deserving urgent attention. Co-operative inquiry was used to analyse attitudinal and structural barriers that perpetuate inequitable treatment of parents with learning disabilities and their children, drawing on policy and practice examples from Australia and the United Kingdom. Bacchi's "What is the problem represented to be?" approach to social policy issues was used to answer the question: *if we know what works to support parents with learning disabilities, why aren't we doing it?* This commentary contends that the pervasive representation of parents with learning disabilities as inherently deficient in the requisite skills ('parenting capacity') needed for safe caregiving has been difficult to shift due to systematic ableism. Neoliberal policies stigmatise a need for support ('dependence') as an individual failing and recast assessments of long-term support needs as an unsustainable burden on support services/systems. We conclude that a social model of child protection that is accessible to all involved returns to principles of interdependence, relationality and ethics of care.

Keywords

co-operative inquiry, child welfare, learning disabilities, parenting capacity, social model, UNCPRD

‘teaser text’ High rates of child removal from parents with learning disabilities is an urgent social policy issue.

The authors used co-operative inquiry to explore why so little progress has been made to keep children with their parents with learning disabilities despite evidence that, with support, they can and do learn to be safe caregivers.

The commentary reports on the use of a social policy analysis approach developed by Bacchi called “What is the problem represented to be?” (WPR). This approach was used to structure an analysis of underlying social attitudes toward parents with learning disabilities and how these attitudes underpin child welfare policies and practices.

The authors show how concepts such as parenting capacity reinforce negative beliefs and assumptions about these parents as incapable and unable to learn. Need and risk assessments are weaponised to show that support needs are an individual failing and too high, which justifies systemic failures.

The commentary concludes with two examples of practice approaches that are consistent with a social model of child protection: the Six T’s and the Three Pillars of Engagement. The values that are embedded in these enable a genuinely rights-based, ethical care accessible to all.

Introduction

We have a considerable body of evidence about parents with learning disabilities based on research conducted across the Global North over the last eight decades. This is an area of increasing significance, and a recent English study found that in one-third (34%) of 200 recently concluded care proceedings, parents had learning disabilities or learning difficulties (Burch et al., 2024), highlighting the scale of the issues faced by this group of parents. This paper primarily focuses on parents with a diagnosed learning disability, referred to in Australia and elsewhere as having intellectual disability, since this is the focus of most of the international literature. However, it should be noted that there is a broader group of parents who have learning difficulties. These are parents who do not meet the formal threshold of having a diagnosed learning disability (IQ of below 70) but experience similar issues in relation to parenting. As a learning disability diagnosis is typically what decides eligibility for access to service provision, those with learning difficulties are often left with less access to support.

Parents with learning disabilities face a disproportionate rate of child removal estimated at around 40% (Llewellyn and Hindmarsh, 2015), although in Burch’s study only 21% of children remained with parents who had learning disabilities or learning difficulties, at the end of Care Proceedings (Burch et al., in press and cited with permission). This form of child welfare disproportionality and the structural and systemic forces that are responsible for it has received far less attention than we believe they should. Whilst there is specific good practice guidance promoting positive support for parents with learning disabilities in three countries of the UK, it is not widely implemented (SCLD 2015; Welsh Government, 2023; WTPN 2021).

The substantial body of evidence from studies on parents and parenting with learning disabilities provides clear and reliable evidence that intelligence – as measured by standard IQ tests - is a poor predictor of parenting ability (IASSID SIRG, 2008), that children growing up with parents with learning disabilities fare as well as their peers from similar socioeconomic backgrounds (Collings and Llewellyn, 2012; Hindmarsh et al., 2013), and that parents with learning disabilities can learn to provide their children with satisfactory care given appropriate support (Collings and Spencer, 2023; Coren et al, 2011; Wade et al., 2008). Not only, then, does the persistently high rate of child removal from parents with learning disabilities present a compelling social issue warranting policy attention and reform, but this situation also represents a clear breach of state responsibilities to uphold Article 23 of the United Nations Convention on the Rights of Persons with Disability (2008), and Article 9 of the Convention on the Rights of the Child (1989). It also does not align with the emphasis and principles found in UK and Australian child welfare legislation that children should remain with their parents, whenever possible.

The authors of this commentary are united by a common and long-standing interest, as scholars and advocates from Australia and the United Kingdom, in advancing the rights and support needs of these families, informed by the best possible research evidence. Jurisdictions in Australia and the United Kingdom demonstrate similar shortcomings when it comes to how child protection and adult (disability) services conceive their roles and responsibilities when it comes to providing “appropriate assistance” (UNCRC Article 23) to parents with learning difficulties to retain care and upbringing their children.

Initially, we came together with the view of co-authoring a joint publication mapping out the issues and identifying potential points of cross-system learning to inform policy and practice development in our respective countries. Our initial discussions, however, led to a deeper contemplation of why only patchy progress has been made to change policies and practices in this field to ensure more parents with learning disabilities retain the care and upbringing of their children.

To explore this issue, we embarked on a cooperative inquiry. Co-operative inquiry is a deliberative process that brings together like-minded people to explore areas of mutual interest, concern or practice (Heron & Reason, 2013; Short, 2018). It is a cyclical iterative process comprising four phases. In phase one, we refined our inquiry question. Put simply, we are asking: *if we know what works to support parents with learning disabilities, why aren't we doing it?* Phase two involved drawing on policy and practice examples from our respective nations, to identify attitudinal and other barriers that sustain inequitable treatment of these families across society. In phase three, to facilitate our analysis, we drew on Bacchi's "What is the problem represented to be?" (WPR) approach (Bacchi, 2012, Bacchi and Goodwin 2016) which offers a critical framework for policy analysis. WPR poses a series of set questions to help surface underlying assumptions beneath social policies, and resultant practices, and the political and ideological positions that underpin 'solutions' to address social problems. Our goal was to explore the consistent barriers that remain in implementing policy and practice in this area as well as shedding new light on this issue to propose a constructive way forward that uphold the rights of people with learning disabilities to form a family. While the WPR framework informed our thinking, it was used as a guide only. In Phase 4, we co-authored this commentary based on the previous phases.

Over a two-year period, we met every month or six weeks by videoconference. Meetings were at least one hour in duration and scheduled around time zone differences of up to 12 hours. We created a repository to share relevant resources and, as the co-inquiry progressed, used a cloud-based document editing program to share individual reflections and to work together. In phase 3, we drafted and reviewed responses to the WPF questions and then discussed and developed our argument during meetings. Each of us continued to refine and edit the argument until there was a consensus on the final draft for submission.

Supporting parents with learning disabilities: The current policy landscape

As discussed above, there is a growing body of evidence that supports the view that parents with learning disabilities can and do become good enough parents when the correct support is in place, and this is reflected in the current policy landscape across the UK and Australia. In England, Scotland and Wales for example, good practice guidance clearly states that parents should be able to access support to parent their children and that this can be long term if necessary (Scottish Commission for Learning Disabilities [SCLD], 2015; Welsh Government 2023; Working Together with Parents Network, [WTPN] 2021). The guidance recognises the importance of early identification of parents and the opportunity for early help and support. The guidance also emphasises the importance of adopting a whole family approach that involves joint work between adults and children’s services as well as a need for accessible and timely information. The Good Practice Guidance (WTPN, 2016 – updated in 2021) was endorsed by the President of the Family Division (covering family courts in England and Wales) in 2018 and has become a template for positive practice (Parents with learning difficulties: risk of harm) [2023] EWCA Civ59). In Australia, a national strategy known as *Healthy Start* bridged the research to practice gap in supporting parents with intellectual disability and their children (see McConnell et al., 2008). From 2005 to 2014, the initiative created a national community of practice to improve professional capacity to work effectively with these families and implemented several parent support interventions that have been adopted internationally (McConnell et al., 2008). In the last decade, Australia has implemented the National Disability Insurance Scheme (NDIS), which promised to reduce service fragmentation and increase choice control for people with disabilities. But, with the defunding of *Healthy Start*, focus on integrated and holistic support for people with intellectual disability who are also parents has been lost (Wedgwood et al., 2021). Mobilised by public attention to issues of interpersonal and systemic violence, abuse, neglect, and exploitation of people with disabilities in Australia (see Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Final Report Australian Government 2023) and to a review of the NDIS, a national advocacy collective of parents and their professional allies has formed to advocate for social justice for families headed by parents with learning disabilities in Australia (Inclusion Australia, 2023).

Adults with learning disabilities who are parents in England are also eligible for support under the Equality Act (2010) and, in the Australian state of Victoria, the Charter of Rights for Parents and Carers with Disabilities involved in Child Protection was recently adopted

(Victorian Government, n.d). The Charter recognises that parents and carers have the right to a relationship with their children and that child protection has a legal responsibility to promote a child’s best interests and safety, and to engage with parents in an open and transparent way.

Yet despite this increasingly favourable legal and policy landscape, a number of barriers remain. We suggest three main reasons for this, which are discussed in more detail below.

Barrier One: Assumptions about parenting with a learning disability

Our use of the WPR framework (Bacchi, 2012) enabled us to unearth a number of historic (and often unspoken) assumptions about the abilities of people with learning disabilities to parent adequately or effectively. We suggest that there are concerns around the permanent nature of a learning disability which is often defined as a “lifelong condition that started before adulthood” (Scottish Executive, 2000, Department of Health, 2001) or as an intelligence quotient (IQ score) of less than 70 which originated before the person turned 18 years of age (Australian Government, 2023), which leads to an assumption that parents with learning disabilities are incapable of overcoming limitations or learning new skills. Secondary analysis of national child protection data in Canada has shown that when the presence of cognitive impairment is noted in an investigation, the outcome is up to four times more likely to be statutory child removal (McConnell et al., 2021), while Burch et al., (in press) found that only 21% of children remained with parents who had learning disabilities or learning difficulties at the end of Care Proceedings. This is also supported by findings from Sigurjonsdottir and Rice (2017), who reported that family courts in Iceland tend to make potentially inaccurate judgements about parenting capacity based on parental intelligence, as measured through IQ testing.

These assumptions are exacerbated by a second set of assumptions that frame adults with learning disabilities as “eternal children” (see for example, Starke et al, 2016) - that is, that adults with learning disabilities are childlike and thus incapable of adult responsibilities such as intimate relationships and childrearing (see for example McCann et al., 2019). These assumptions can result in people with learning disabilities being denied appropriate and timely sexual health information, guidance and support to enact their reproductive rights (McCann et al, 2019) as is required under Section 23 of the Convention on the Rights of

Persons with Disability (United Nations, 2008). To the extent that they do receive any sexual and relationship health education, the focus is typically on contraception rather than intentional family planning (Frawley et al 2022). Studies have shown that family members of a person with learning disabilities often actively discourage their sexual expression (Charitou et al., 2022) and news of pregnancy is often greeted with disbelief and concern, rather than excitement and congratulations, by family (Booth and Booth, 1995; Mayes, Llewellyn, and McConnell 2006). Parents with learning disabilities receive the message that they have done something wrong and the stigma they experience can discourage them from seeking help; unmet needs compound and increase a risk of child protection intervention (Wedgwood et al., 2021). These assumptions are often accompanied by the suggestion that parents with learning disabilities cannot be trusted to make appropriate parenting decisions (Tilbury and Tarleton, 2023). Taken together, these assumptions can lead to a conclusion that the State must act preemptively to prevent potential harm to a child by removing them from a parent with learning disabilities.

These assumptions may not be held consciously but rather operate at a subconscious level, supporting negative attitudes and beliefs about learning disabilities. In other words, it might be ‘felt’ by the general public, and social workers and legal professionals that adults with learning disabilities cannot (or should not) parent. Recent UK studies revealed negative assumptions about parents who needed a high level of support (MacIntyre et.al, 2019; Tilbury and Tarleton, 2023). This is despite the fact that social, political and structural changes are resulting in increased numbers of people with learning disabilities exercising their right to have children (IASSID SIRG, 2008).

We suggest these assumptions represent an attitudinal legacy that can be tracked back to earlier eugenicist ideas. As far back as the late 18th century, there were those who asserted that the survival of humankind relied on the eradication of genetic weaknesses by ensuring particular groups, including the ‘feeble-minded’ (i.e., those with learning difficulties), did not procreate (Garton, 2010). Widespread use of policies and practices such as forced sterilisation (‘positive’ eugenics) and same-sex segregated institutionalisation (‘passive’ eugenics) were sanctioned during the first part of the 20th century (McConnell and Phelan, 2022). While legislative restrictions on the sterilisation of women with disabilities have taken place and social policies have been introduced across the Global North to promote deinstitutionalisation, the attitudinal legacy of the old eugenics can still be seen in later forms

of 'newgenics'. This term is used to describe a range of medical, social and political practices to eradicate conditions deemed a burden on society (Malacrida, 2019). We argue that overt and covert forms of eugenics are reflected in child welfare and disability policies and practices that continue to deny or diminish opportunities for persons with learning difficulties to have access to sex education, sexual encounters, family planning, and appropriate assistance to parent when they do have a child.

Newgenics is closely associated with ableism as a silent and unproblematized thread that runs through the assumptions discussed above. Ableism takes the form of unconscious bias against people with learning disabilities who choose to become parents, resulting in negative attitudes from professionals and others who can potentially follow them throughout their parenting lives. Evidence suggests that unconscious bias dominates child welfare processes, including in parenting assessments and legal decisions (Aunos and Pacheco 2021; Callow et al., 2016; Malacrida, 2009; McConnell et al 2021; Sigurjónsdóttir and Rice, 2016) and can combine with systemic discrimination and structural barriers that lead to health disparities and social disadvantage for people with disabilities in general, and those with learning disabilities more particularly (Fisher and Purcal 2017; IASSID SIRG, 2008). As Llewellyn and McConnell (2010) state, “systemic barriers that flow from beliefs that intellectual [learning] disability means ‘less than’” means that parents with learning disabilities have to work especially hard to prove themselves (p 463).” As one of the reviewers of this commentary astutely noted, “It can seem that the human rights and positive policy statements/guidelines cruelly hold out the prospect of rights to parenthood that the state has a duty to support while operating in practice to deny these rights.”

Barrier Two: (Mis) understandings about the nature of the parenting role and task

We argue that alongside these assumptions around the capacity and suitability of people with learning disabilities to parent are a number of assumptions about the nature and role of parenting that are built into assessments of parenting capacity. Again, these assumptions are often unspoken, but we suggest that they presuppose that parenting is a task that is typically performed independently (without significant external or state support). This feeds into a feeling expressed by parents (Tarleton and Porter, 2012) that they are being held to a different and higher standard of childcare, in contrast to most parents who typically receive support from social networks and can avail themselves of accessible universal social services

(Wedgwood et al., 2021). Parenting as an *interdependent* activity is cast aside in the quest to determine whether a parent is (in)capable of keeping their child safe without the need for high-level support provided by the State. If parenting is viewed, in assessment terms, as a highly individualised activity, the resource implications of providing support for a parent with a learning disability is likely to be significant. Providing support over extended or recurrent periods is likely to be expensive and so parenting assessment may be subtly reframed as a question not of individual capacity but of resource allocation and viability (Collings et al, 2022; Tibury and Tarleton, 2023).

Barrier Three: The Political and Organisational Context

These attitudinal barriers combine with a political and organisational context that has been dominated by neoliberal political ideologies that gained prominence across much of the Global North, including Australia and Britain, over the last few decades. Policies to address social inequalities have been dominated by concepts of individual responsibility and trickle-down economics (Spolander et al., 2014) and welfare provision to our most vulnerable members of society has been marketized, with support converted into a commodity (Featherstone et al, 2014). The consequences are that child and adult services have become increasingly risk-averse, time-limited, performance and task-focused, and heavily outcome-oriented (Featherstone et al., 2014). Interventions are made to resolve the presenting issue and close the case rather than to provide support over time. This, combined with short timeframes for statutory child protection decision-making and assessment, undermine professional engagement with parents and opportunities for relationship-based practice (Ruch et al., 2018). Furthermore, research clearly shows that many workers feel out of their depth when it comes to supporting parents with learning disabilities within the constraints of time-limited and under-resourced service systems (Clayton et al., 2008; Norlin and Randell, 2022; Proctor and Azar, 2013). These organisational and political barriers combine with the attitudinal barriers discussed above to create a support environment that can be hostile to the needs of parents with learning disabilities, despite a more favourable policy landscape and growing evidence base around what works.

What is needed: A reconceptualising of interdependent parenting

We argue that a far-reaching reform agenda is essential if we are to move to a situation where parents with learning disabilities are empowered to parent through the provision of appropriate support. This will mean thinking seriously about our perceptions of adults with learning disabilities, including the stigma they face and the way in which poor environments and lack of resources inhibit their ability to parent well. Indeed, some assessment frameworks have been designed for use with parents with learning disabilities, which take account of environmental supports and barriers, and promote a focus on competencies not just limitations (for example, Feldman and Aunos 2010), illustrating the type of approach we are advocating here.

Rethinking support for parents with learning disabilities also requires us to (re) conceptualise parenting, by accepting that parenting is ‘interdependent’ in nature and that parents with learning disabilities are not unusual in needing on-going or recurrent support with their parenting. This involves moving towards a more relational and care-informed way of working with an associated shift away from the more directive or task-focused approaches that hold sway in many over-stretched and under-resourced social care services. This approach is underpinned and informed by the framework offered by Tronto (1993, 2017), and we would promote an approach grounded in an ethic of care that demonstrates:

1. *Caring about*. At this first phase of care, someone or some group notices unmet caring needs.
2. *Caring for*. Once needs are identified someone or some group has to take responsibility to make certain these needs are met.
3. *Caregiving*. The third phase of caring requires that the actual caregiving work be done.
4. *Care receiving*. Once care work is done, there will be a response from the person [...] that has been cared for. Observing that response, and making judgements about it (for example, was the care given sufficient, successful or complete?) is the fourth phase of care. [...]
5. *Caring with*. Caring with occurs when a group of people (from a family to a state) can rely upon an ongoing cycle of care to continue to meet their caring needs. (Tronto, 2017, pp.31-32)

Such an approach, while acknowledging the interdependent nature of parenting and normalising ideas around parenting support, also acknowledges that we all have the potential to be vulnerable and require support at different points in our parenting lives. Indeed, as Beckett (2006) argues, vulnerability is something that anyone can experience, and any individual may be susceptible to a wide range of risk factors and new forms of exclusion over the life course. This challenges the idea of the independent/autonomous parent who makes no demands on others, recognising that we all need support in different ways and at different times to parent to our best ability.

This re-framing of ideas about vulnerability, dependence and individual responsibility aligns with a feminist ethics of care that highlights our complex *interdependencies* (Barnes et al, 2015) as we take on roles where we both give *and* receive care. Taking this perspective allows us to change the narrative about what constitutes support for parenting, how it is provided, by whom and to whom. Parents with learning disabilities want and need support that is neither unusual nor unreasonable. An ethics of care approach in responding to parents with learning disabilities could significantly change the perspective and methods used in social care services. This approach focuses on empathy, understanding, and meeting individuals' needs.

We recognise that the cost of providing this support for parents with learning disabilities is more likely to be borne by the state, than may be the case for other parents, given what we know about their more limited support networks (Llewellyn and Hindmarsh, 2015). Indeed, it is often the case that parents with learning disabilities lack positive parenting role models that they can call on for support in times of crisis and, importantly, less positive life experiences to draw on as they develop their own parenting style and skills (Cleaver et al, 2011). Yet evidence suggests that when parents with learning disabilities have positive support from family members or other social networks, they are more likely to cope with parenting challenges (Wilson et al., 2014). UK research has shown that investing social care funds in advocacy support for parents with learning disabilities at risk of losing care of their children is likely to deliver a positive return on investment both for social services and the wider public sector in the short and long term, not to mention the likely benefits to flow from improved quality of life for parents and children (Bauer et al, 2013). In this vein, we argue that it could well be less costly (emotionally and financially) to provide timely support to parents with learning disabilities than the current crisis intervention model resulting in the

form of child protection investigation, court processes and out of home care placement. Further work involving a more detailed economic analysis would be helpful in this regard (see for example, Bauer, et al, 2013).

A different way forward?

As Featherstone and colleagues (2014) have argued, child protection can learn from the disability sector about how to promote a ‘social model’ of practice grounded in reflexivity that acknowledges the structural forces that impinge on parents with learning disabilities and on social workers’ own ability to respond within the system constraints they face. The social model advocates practice developments that are underpinned by a rights-based framework that takes as its guiding principle the necessity to co-design disability-informed practices with families and workers (Collings and Spencer, 2023). This also responds to a need for child and family workers to feel supported in working effectively with parents with learning disabilities (Norlin and Randell, 2022; Proctor and Azar 2013).

Recognising the need for a change of pace – for a form of ‘slow social work’ (Bozalek, 2021) - does not mean that practice stops being purposive. Rather it provides the conditions for more relational engagement between professionals and parents with learning disabilities. Practice models that are consistent with this approach, developed by the authors, include the ‘6Ts’ and the Three Pillars of Engagement. The 6 T’s require workers to take extra **time** with parents to build **trust**, display **tenacity** to tackle the issues as they arise, **truthfulness** and **transparency** so that parents really understand what is happening, why and by whom, which ensures **tailored** support for the parent and family (Tarleton and Turney, 2023). The Three Pillars of Engagement is grounded in principles of reciprocity, mutuality and relationality. For both parent *and* worker to be **available** to engage, they need resources, including time and finances; a belief that what is on offer is **relevant** to their circumstances; and trust that it is **safe** to engage in the process (Collings et al, 2022). This type of support could be regarded as part of our nations’ respective obligations under Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (Article 23 to provide “appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities”, providing ‘reasonable adjustments’ in relation to parents needs under the Equalities Act 2010 (UK) and ‘reasonable and necessary support’ under the National Disability Insurance Scheme Act 2013. This type of support is accomplished through multi-

agency working and through the development of inter-agency protocols and joint funding of support packages (Tarleton et al 2018, WTPN, 2009).

Conclusion

We started this Commentary by noting that the problematic representation of parents with learning disabilities as inherently deficient in the requisite skills (parenting capacity) is an attitudinal legacy that remains pervasive and difficult to shift. This is compounded by a neoliberal agenda: we have seen how a need for support becomes stigmatised, located as an individual failing and divorced from the social and relational contexts that parents with learning disabilities and their families navigate. An assessment of the need for long-term or recurrent support is recast in policy and practice as unmanageable and unsustainable, perhaps unreasonable – distinct from the kinds of demands that other parents make on support services/systems.

Our analysis indicates that we need to change the systems of child protection and family support to better enable families to flourish. It has been argued that this requires an approach founded on the principles of interdependence and an ethics of care that is currently embodied in ideas around a social model of child protection (Featherstone et al, 2014) with a return to relational or slow social work that is preventative rather than reactive to family needs and concerns, and grounded in an ecological understanding of the worlds that families live in. But even this will only be effective if we have the values in place to enable us to build genuinely rights-based, ethical care accessible to all.

In this commentary, we have made an active choice to adopt a hopeful stance in terms of what is possible in terms of realising the rights of parents with learning disabilities.

Moreover, social workers have a crucial role to play in advancing reproductive justice for parents with learning difficulties and realising their rights under Article 23 of the CRPD. In practical terms, how can this be done in practice?

- (1) Be critically reflexive. Ask yourself, “What assumption do I hold about parents with learning difficulties?”
- (2) Work with one parent at a time. Use as your guide the three pillars of engagement model and work according to the six Ts.

- (3) Call out ableism when and wherever you encounter it.
- (4) Be a subversive change agent within the system. Use the UNCRPD and other good practice guidelines (for example, the WTPN 2021 to advocate for appropriate assistance and accommodation for parents with learning disabilities).
- (5) Showcase good practice that happens against the odds (giving hope).
- (6) And when things don't go right ...ask why?
- (7) Find allies. Form a community of practice with like-minded social workers and be willing to challenge each other in a spirit of shared purpose.

Finally, remember there are lots of areas in social work where addressing injustice and bringing about social change is 'glacial slow', but that does not and should not draw us to pessimism and complacency; if anything, and we are being true to our social work values, it should embolden us.

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