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Challenges to Realizing the Convention on the Rights of Persons with Disabilities (CRPD) in Australia for People with Intellectual Disability and Behaviours of Concern

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It has been a significant period of time since Australia ratified the United Nations' *Convention on the Rights of Persons with Disabilities 2006* (CRPD). While the CRPD brings significant positive changes in legislation, public policy, and service delivery (for example, in the National Disability Insurance Scheme), there are still a number of challenges in implementing the CRPD in Australia, particularly for people with intellectual disability who exhibit behaviours of concern. Some of the challenges include a negative perception of disability, the misrepresentation of occupational health and safety frameworks, and a revival of the call for congregate care living. Given these barriers to full CRPD realization, some of the solutions may include a closer engagement with families, other legislative frameworks, and industrial relations, and a stronger monitoring role for the CRPD implementation in Australia.

Keywords: challenging behaviour; Convention on the Rights of Persons with Disabilities (CRPD); disability services; human rights; intellectual disability; occupational health and safety (OH&S).

Introduction

It has been a significant period of time since Australia ratified the *United Nations Convention on the Rights of People with Disabilities* (2006; CRPD in July 2008). As such, it is timely to reflect on the CRPD implementation, in particular for people with intellectual disability who exhibit behaviours of concern (such as physical aggression, property damage, self-harm, or sexual offending). It is important to note that the CRPD applies to all people with disabilities and mandates a social model as fundamental to the realization of human rights. It represents a significant shift from the welfare and medical approaches, and it emphasizes the removal of barriers and positively changing the social contexts in which people with intellectual disability live (French, 2007). The purpose of the CRPD ' . . . is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity. People with disabilities include persons with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (CPRD, p. 4). There is other commentary or further analysis on the significance of the CRPD (e.g., Kayess & French, 2008); never-

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theless it is important to reiterate that the CRPD has significantly changed how we view people with disabilities.

People with intellectual disability and those who exhibit behaviours of concern are especially in need of monitoring to protect their human rights because they are often disadvantaged by a wide range of physical, psychological, and social factors. Some of these factors include poor health care, presence of mental illness, and a deprived social—economic status and education (Allen, 2008; Beange, McElduff, & Baker, 1995; Emerson & Durvasula, 2005; Lennox et al., 2007). These factors put them at risk of offending and developing behaviours of concern (Allen, 2008; Chan, French, Hudson, & Webber, 2011; Emerson & Einfeld, 2011; A. Holland, 2004; S. Holland, Persson, McClelland, & Berends, 2007; Lindsay, Sturmey, & Taylor, 2004).

The behaviours of concern often result in these individuals being accommodated in closed environments (such as residential institutions or detention centres). This in turn places them at further risk of abuse and restrictive practices, can exacerbate mental illness, and contributes to an increase in behaviours of concern (Allen, Lowe, Brophy, & Moore, 2009; Chan, LeBel, & Webber, 2012; Fitzsimons, 2009; Hayes, 2004; McVilly, 2004; Webber, McVilly, & Chan, 2011). The impact of restrictive practices on these individuals can be detrimental and tragic (Chan, Arnold, et al., 2012; McGill, Murphy, & Kelly-Pike, 2009; Nunno, Holden, & Tollar, 2006). Many of them also experience difficulties in integrating into the community or finding suitable options in the community as a result of prolonged stay in these environments (Allen et al., 2007; Hayes, 2004; S. Holland et al., 2007). The degree to which they are isolated and have fewer opportunities to interact with people outside these settings increases their vulnerability and powerlessness (Fitzsimons, 2009).

Chan, French, and Webber (2011) argued that the CRPD is consistent with positive behaviour support as an approach to ensuring that the rights of people with behaviours of concern are fulfilled. In particular, people with behaviours of concern are entitled to protection from violence, abuse, torture, and cruel and degrading treatment (see, for example, *Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment*, *Article 17 Protection of the integrity of the person*; Chan , French, & Webber, 2011). While the CRPD enshrines the protection of these individuals' rights, there are other challenges that may limit the full realization of their rights. These challenges are explored in this article because behaviours of concern, the geographical isolation of being accommodated in closed environments, and being subject to restrictive practices are not the only risk factors of human rights abuse. The challenges explored here are not an exhaustive list but it is aimed to highlight a few challenges that pose a barrier to the full realization of the CRPD for people with intellectual disability and behaviours of concern.

How Disability is Viewed by Society as a Barrier to Full Realization of the CRPD

How disability is viewed by society and more so for people with behaviours of concern presents as a barrier to full realization of the CRPD for them. While there has been significant progress in defining and recasting disability from a pathological to a social model (Perlin, 2012), people with intellectual disability are still treated and viewed negatively. This negativity is evident in today's culture — such as the bullying of children with a disability in educational and social settings (whether it is name-calling such as 'retarded' or 'defectives' to name but two of the derogatory terms, physical violence, or the use of restrictive interventions or exclusionary practices; Victorian Equal Opportunity and Human Rights Commission, 2012); the stereotypic casting of disability; or the violence experienced by people with disabilities in society (Fitzsimons, 2009).

Another example of the negative perception of disability is evidenced in media reports that portray people as 'suffering from' a disability (Chan, 2013). Accommodating people in closed environments continues to reinforce the negative perception of disability. These images include but are not limited to the perception of 'difference', 'dangerousness', or as a 'social problem'. The fundamental difficulty with this negative perspective is that it fails to consider the lived experience of people with intellectual disability, and underlying this negative perception is the denial of their fundamental human rights (Owen, Griffiths, Tarulli, & Murphy (2009).

The use of language and the historical contexts in which disability is addressed as a social problem (Braddock & Parish, 2001) also play a part in the professional, academic, and medical descriptions of disability. These views in part contribute to the legal, medical, and clinical descriptors of disability. For example, terms such as a person is 'suffering' from 'mental retardation' or a 'mental infirmity' continue to be used in the criminal justice system (such as in courts). Clinical terms and descriptors of various aspects of disability reinforce a negative view of disability. For example, terms to describe some behaviours have included 'aberrant', 'destructive', 'disruptive', or 'problem', which focus on the observed behaviour rather than the underlying causes or triggers for these behaviours (Chan, LeBel, & Webber, 2012).

While there are significant scientific developments that are shifting the construct of disability from pathology to a socio-ecological and person-environment focus, researchers and clinicians must ensure that scientific representations and descriptors of disability uphold the dignity of the person (Chan, LeBel, & Webber, 2012). Therefore it is critical that clinical practice is aligned with the CRPD because failure to do so will add to the negative perception of people who exhibit behaviours of concern (Chan, French, & Webber, 2011; French, Chan, & Carracher, 2010).

Occupational Health and Safety Versus Human Rights as a Challenge?

Occupational health and safety (OH&S) laws in Australia are being misinterpreted and implemented in ways that hide the dilemma of human rights realization for people with intellectual disability and behaviours of concern. Both OH&S and the positive behaviour support paradigm focus on prevention of the 'hazard' or behaviour of concern. Thus there is common ground between both paradigms. A fundamental problem with the misinformation and misrepresentation of the OH&S legislation in observed practice in Australia is the perception that OH&S and human rights are mutually exclusive. It is not uncommon to find people with disabilities in Australia being marked with a 'practice improvement notice' (PIN). Basically, though, this states that the person and/or the person's behaviour(s) are an 'occupational 'hazard' (Victorian Equal Opportunity and Human Rights Commission, 2012). The following examples used to illustrate the point are based on a conglomerate of real examples in disability service provision.

Jacob was a 20-year-old man with a severe level of autism and with behaviours of concern that included physical aggression and elopement. Jacob has been contained and secluded in a semirural home. In one of his weekly outings, Jacob refused to return to his room. Instead, he ran towards the front gate. A staff member chased after Jacob and got hold of him; both fell to the ground as a result. The staff member sustained soft tissue injuries to the legs and arms. The incident resulted in an OH&S inspection, and the local OH&S representative recommended the use of psychotropic medication for Jacob. Furthermore, the local OH&S representative directed a PIN notice, and Jacob was deemed to be a 'hazard', and community outings were also considered a 'hazardous' activity. This resulted in the suspension of Jacob's community outings.

Another example is Sarah who had lived in an institution for many years. It was

reported that Sarah showed a severe level of physical and verbal aggression and caused property damage when she lived in an institution. However, her behaviours of concern had reduced significantly since she moved into her own home and as she started to acquire more skills in independent living. Recently, Sarah and a staff member had an argument when she did not follow the staff member's instruction on mopping the kitchen floor. It was reported that Sarah yelled and waved the mop threateningly at the staff member. She also slammed the mop against the kitchen door, and the staff member was stressed by the incident. As a result of Sarah's behaviour, the OH&S representative recommended that all items that may potentially be used as a 'weapon' were to be locked away. These items included the mop, the broom, utensils, and cutlery. She could only access these items under staff supervision.

It is not the purpose of this article to analyse the case examples above or to comment in detail on the problems inherent in the apparent application of the OH&S legislation and the breaches of human rights in such examples, other than to reiterate that these examples are not uncommon. It is also important to reiterate that disability support professionals should be able to perform their duties safely and without harm. However, OH&S implementation and the lack of understanding from both sectors remain a growing concern for people with intellectual disability and behaviours of concern in terms of the full enjoyment of their rights in relation to how services are delivered and implemented on a day-to-day basis.

The growing reference to OH&S legislation to justify increased use of restrictive practices or to limit the fundamental rights of a person in disability settings is concerning. For example, in Jacob's case, there had been no request to a behaviour support practitioner to examine the underlying causes of Jacob's behaviours, especially when suspending community outings would aggravate his behaviours of concern and reduce his quality of life. Furthermore it appeared that the staff member's injury took precedence over Jacob's rights of freedom of movement and integrity. Jacob was referred to as an OH&S 'hazard'. It is a term that demeans Jacob as a person and his human dignity. Similarly in Sarah's case, the OH&S action to withdraw day-to-day items without a full interrogation of the incident limited Sarah's full enjoyment of her rights and reduced her independent-living skills.

The brief analysis above demonstrates a need to explore human rights in the context of OH&S. For example, what is the recourse for legal counsel representation for the person with intellectual disability in such matters? What is the legislative protective framework, and what is the mechanism to trigger legal representation for the persons subject to a PIN notice? Currently there is no systematic process to ensure that the rights of people with intellectual disability and behaviours of concern are protected on matters relating to OH&S. Advocacy may be ad hoc and only when there is already an existing advocacy for the person or when a referral is made. There are no published data or research in this area currently.

Another question to consider is how disability service providers and OH&S representatives through their local committees undertake an evidence-based practice evaluation and transparent discussion of OH&S legislation interpretation that protect the rights and safety of both staff members and people with behaviours of concern. For example, in Jacob's case, the recommendation of the OH&S representative for the use of psychotropic medication was certainly outside the scope of such a role. Therefore local OH&S committees can benefit from having clearer description of roles, a proper and timely process for referrals to relevant professionals for assessment of the incidents, and a better understanding of therapeutic frameworks in supporting people with behaviours of concern.

Hence, industrial relations are clearly an area that human rights agendas need to

engage with. A constructive dialogue is critical to a successful implementation of human rights particularly in terms of people with intellectual disability and behaviours of concern, or those who have high and complex needs. It is clear to everyone that staff safety is paramount in any work environment and more so in close environments where there are people who present with significant behaviours of concern. Often in trying to resolve these issues, there is a tendency to debate the matter as if human rights and staff safety are competing with each other. For example, it is not uncommon for the union to argue for the necessity of the use of restraints, in particular the use of prone or supine restraints despite the fact that this practice is not safe for the person and staff (Chan, Arnold, et al., 2012a)

What is often overlooked in the industrial relations debate is that there are other alternatives to the use of restraints and seclusion, such as a positive behaviour support model. Positive behaviour support is an evidence-based therapeutic approach that is used to assess and support a person presenting with behaviours of concern. This approach neatly aligns with the CRPD (Chan, French, & Webber, 2011b). Furthermore, the positive behaviour support model is similar to the OH&S approach—that is, it is about preventing the behaviour of concern or the 'hazard' before it occurs. Rights protection for employees and people with intellectual disability must go hand in hand.

The Revival of the Call for Congregate Care Living

Past service models are being reinvented using language that denies the human rights of informed consent and supported decision making by people with intellectual and developmental disabilities. These pose a challenge to human rights implementation in Australia. In Australian disability settings, there is a revival of the call for congregate care or segregated living for people with disabilities as

an answer to the concerns of many families about the lack of suitable accommodation (Burin, 2011; Guy, 2003; Reilly, 2011). Families and carers of people with disabilities need assistance so that they can continue to care for their loved ones. Without timely and an adequate level of responsive services, many families will experience an adverse impact on their lives, from psychological to financial costs (Lewis & Johnson, 2005).

The revival of congregate settings today utilizes new terminology – 'intentional communities' (People with Disability Australia Incorporated, 2009). The notion of an 'intentional community' is contentious and has stirred debate in the disability services sector (Bigby, 2011; Burin, 2011; Reilly, 2011). There is merit in the notion of 'intentional communities' when a person has the capacity to consent, to subscribe (and unsubscribe) freely, and to join or leave such a community, and when they are supported to make such significant decisions. However, inadequate consideration is being given to how consent is safely and appropriately applied to people with intellectual disability when congregate care is being considered for them.

The turning back to congregate and segregated care living is concerning when there is substantial international research to indicate that the benefits of small homes far outweigh institutional or congregate care living (Bigby, 2011; Felce & Emerson, 2005). The history of institutions strongly indicates that such a model of living is incompatible with human rights, particularly as it is inconsistent with *Articles 18, 19, and 20* of the CRPD. *Article 18* articulates the right to liberty of movement and nationality. *Article 19* explicitly reinforces the right to independent living and inclusion in the community and to prevent isolation and segregation from the community. *Article 20* reiterates a right to independent living to the greatest extent possible by ensuring personal mobility.

Another area of challenge for human rights implementation is to begin a dialogue

for human rights within the family context. There need to be more opportunities for families and community members to evaluate whether congregate care living, in particular the notion of isolated farms and isolated intentional communities, is right for them or whether it will reinforce segregation and the myths about disability. When families are adequately supported, and their relatives with a disability are provided with a range of community-based accommodation options, appropriately supported and included in society, then they may be less inclined to turn to congregate care models as an answer to their concerns.

Conclusion

This article reflects on some of the challenges in human rights implementation since Australia ratified the CRPD. It has attempted to illustrate how society in general continues to view disability negatively and how this negative perception impacts on people with disabilities, especially those with behaviours of concern. It also proposes the need for human rights discourse to address other legislation such as OH&S because of its potential to affect the daily lives of people with disabilities. It highlights how the misinterpretation of OH&S entitlements can impact on the rights of people with an intellectual disability, particularly those who exhibit behaviours of concern. There are few legal options afforded to people with an intellectual disability when they are subject to a PIN notice. There is a consequential risk to their rights being unnecessarily eroded. Another barrier explored is the revival of the call to congregate care living for people with disabilities; this poses significant challenges to the full realization of the CRPD.

In Australia, many statutory bodies and advocacy agencies have been established to safeguard the rights of people with disabilities, particularly in the state of Victoria where there are the Disability Services Commissioner, Senior Practitioner, Public Advocate, and Community Visitors (Chan, 2013). While each plays an important function, there are overlaps and complexities in the existence of multiple agencies.

It would be useful too to consider how the CRPD could be more strongly enlivened within Australia and in the Asia Pacific region. An option in this regard would be the creation of a regional human rights commission. Perlin (2012) puts a convincing argument for how a Disability Rights Tribunal could be effective in enabling the CRPD to provide a greater level of scrutiny and greater recourse to people with intellectual disability to have matters of human rights infringement being heard. A tribunal would provide an avenue for people with intellectual disability to raise concerns directly and could also act as a monitoring body for rights implementation. This proposal deserves further consideration as it would empower those with intellectual disability. For example, such a proposal may potentially address the right of recourse for people with an intellectual disability subject to an OH&S PIN notice. Furthermore recognition of such barriers could provide an opportunity for the disability service sector to address such issues and to increase their engagement with human rights advocates.

The CRPD is a significant paradigm shift in how disability is viewed. It has also impacted positively at the level of public discourse and social policy, and in the development of legislation. However, there is more to be done to address some of the challenges explored in this article because the lives of people with intellectual disability who display behaviours of concern cannot remain in a holding pattern or revert to the previous era of institutionalization − particularly when congregate care living may repeat previous history and narrative of a demeaning view of people with disabilities. Hence, there is a need for the monitoring of the implementation of the CRPD in Australia so that there is progress in fully realizing the rights of people with disabilities.

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