



Rights Are Necessary but Insufficient for the Achievement of the Full Inclusion of People with Intellectual and Developmental Disabilities

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Accepted: 17 July 2023 / Published online: 3 August 2023
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Abstract

Objectives Two forces which are in juxtaposition have been impacting upon the achievement of full inclusion and emancipation of people with intellectual and related developmental disabilities into society. The first is the history of the United Nations human rights declarations and conventions. While human rights initiatives have supported grassroots movements such as choice, self-determination, and person-centred supports, the second force, neoliberal philosophy, has commandeered these concepts into a culture of managerialism and individualism. Whether rights are necessary but insufficient for the achievement of the full inclusion of people with intellectual and developmental disabilities needed to be addressed.

Methods The history of the human rights movement was explored leading up to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The impact of countervailing forces of neoliberal policies were explored. The ongoing development of models of disability were examined, as were threats to implementation and the realisation of outcomes.

Results The impact of neoliberal policies by member nations and the juridical nature of the CRPD were found to be limiting factors for genuine community acceptance and inclusion of people with disabilities, especially those with intellectual disabilities.

Conclusions Member nations conforming to human rights imperatives also need to encourage the building an ethical community in which reciprocal relationships are fostered and celebrated. Individualism and the market-based economies have failed to recognise the important role communality has played in the history of the human species.

Keywords Intellectual disabilities · Human rights · Inclusion · Self-determination · Individualism · Managerialism · Neoliberalism · Ethical community

Before analysing the roles, human rights may play in the full and genuine inclusion of people with intellectual disabilities it is useful to examine the history of the concept. The trajectory of human rights can be traced back to antiquity, growing out of the Greco-Roman concept of natural law which emphasised the notion of duties rather than rights. Following the end of the Middle Ages, the English, American, and French revolutions saw a change from the concept of natural law to that of natural rights, illustrated by events such as the French Declaration of the Rights of Man and of the Citizen (1789), the English Bill of Rights (1689), and the Bill of Rights in the United States Constitution (1791).

The emergence of the Enlightenment era also heralded the principles of the rights to life and liberty and the rights of freedom of speech and worship. Liberal philosophers John Locke, Immanuel Kant, Jean-Jacques Rousseau, Voltaire, Thomas Paine, and John Stuart Mill were at the forefront in discovering and acting upon universally valid principles governing nature, humanity, and society, including the inalienable “Rights of Man,” which they treated as a fundamental and ethical (Nickel, 2006).

In the late 19th and early 20th century, natural law and natural rights came under attack from legal thinkers, who insisted that rights are ultimately founded upon utility (Escamilla, 2008). This view was supported by the German jurist, Friedrich Karl von Savigny (Beiser, 2011), and England’s Sir Henry Maine who emphasized that rights are a function of cultural and environmental variables unique to particular communities (Cocks, 2004). In the lead up to World War I, there were few theorists who were defending the “rights of man” along

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the lines of natural law, influenced in part by the growth of German idealism, based on the works of Kant, Hegel, and Fichte and European nationalism (Hammer, 2007; Llewellyn & Thompson, 2020). In the context of people with intellectual or other cognitive impairments, contemporary political theorists and moral philosophers have critiqued or adapted liberal theory (Clifford Simplican, 2015; Francis & Silvers, 2010; Kittay & Carlston, 2010; Mitra, 2006; Nussbaum, 2009; Vorhaus, 2005). For instance, Francis and Silvers (2010) have questioned whether liberal theorists have failed to commit to the inclusiveness of people seen as “outliers.” It was probably no coincidence that the eugenics movement which sought to improve the genetic quality of the human race also flourished at this time and continued through to World War II and beyond, as evidenced in some jurisdictions where sterilisation laws were not suspended until recent years (Reinders et al., 2019).

The rise of the Nazi regime in the early 1930s and its early atrocities on marginalised groups such as the Roma population and people with intellectual and other developmental disabilities were prompted by the eugenics concept of racial purity. This policy then underpinned the vilification and subsequent elimination of people of Jewish heritage. As World War II came to an end and the atrocities were fully revealed, the more modern concept of human rights was illustrated in the Charter which led to the establishment of the United Nations. All member states pledged to take joint and separate action for the achievement of “universal respect for, and observance of, human rights and fundamental freedoms for all without distinction as to race, sex, language, or religion” (United Nations, 1945, Article 55).

Subsequently, the United Nations promulgated the *Universal Declaration of Human Rights (UDHR)* (United Nations, 1948) which had inspired and paved the way for the adoption of over seventy human rights treaties, including the *Declaration of the Rights of the Child* (United Nations, 1959), followed by the *Convention on the Rights of the Child* (United Nations Children’s Fund (UNICEF), 1989). At this point, it is important to distinguish between a “Declaration” and a “Convention” in the context of the United Nations. Declarations have no legal binding but carry a strong moral force for international community commitment. In contrast, a Convention is a ratified treaty or a binding formal agreement which again in the context of the United Nations, signatory countries have a legal obligation to respect, protect, and fulfill the rights written in the Convention.

For people with a disability, the first human rights initiative by the United Nations was the *Declaration of the Rights of the Mentally Retarded* (United Nations, Office the High Commissioner Human Rights (OHCHR) 1971) which was influenced by the growing deinstitutionalisation movement in Western jurisdictions and the strong lobbying from parent advocacy groups such as the International League of Societies for the Mentally Handicapped (ILSMH).

The key statement in this Declaration was that the mentally retarded person has the same rights, to the maximum degree of feasibility, as other human beings. Other points included the right to proper medical care and physical therapy; the right to economic security and a decent standard of living, including the right to perform productive work; and the right to live with their own family and participate in different forms of community life, with the family receiving assistance. The *Declaration of the Rights of Disabled Persons* followed (United Nations, Office of the High Commissioner Human Rights (OHCHR) 1975). The United Nations General Assembly proclaimed 1981 as the *International Year of Disabled Persons*, followed by a proclamation that 3 December each year would be the *International Day of People with a Disability* (United Nations, Department of Economic and Social Affairs Disability, 1976)

The United Nations General Assembly adopted the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations, Department of Economic and Social Affairs Disability, 1993) which included the appointment of a Special Rapporteur to monitor the implementation of the Rules. This was an important harbinger for the adoption by the General Assembly of the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006). Significantly, a Committee on the Rights of Persons with Disabilities (CRPD Committee) consisting of experts was established to monitor the observance of the Convention. States Parties are now required to provide reports to the Committee every two years including a comprehensive explanation on the progress made towards implementation of the Articles of the Convention, highlighting what Mladenov (2012a) referred to as the juridical aspect of the Convention.

A Paradigm Shift

In the lead up to the actual structure and content of the CRPD by the Ad Hoc Committee (AHC), established by a resolution of the General Assembly (United Nations, Department of Economic and Social Affairs Disability, 2001), there was active commentary concerning issues regarding the definition of disability and the models of disability which drove the process. There was much debate on how to define “disability,” given its history being grounded in what was referred to as the “medical model” where the defining aspect is an impairment inherent to the person. Mladenov (2012a) highlighted the fact that the CRPD is praised as representing a “paradigm shift” away from the medical model (see also, Arnardóttir & Quinn, 2009). He asserted that this is a “...transformation of the very understanding of the disabled people’s “way of being”- in other words, it has profound existential-ontological consequences” (Mladenov, 2012a, p. 72).

The paradigm shift concept was echoed by Series (2020) who suggested that Hammarberg (2011), a former Council of Europe High Commissioner on Human Rights, captured the spirit of the Convention when he wrote:

The last decades have been marked by a shift in thinking. From viewing disability as a personal problem that needs to be cured (the medical model), we have come to see the source of the problem: the society's attitude towards person with disabilities. (Hammarberg, 2011, p.639).

The drafters of the CRPD were not able to agree upon a clear definition of “disability” some of which may be attributed to language and interpretative difficulties together with differing positions on the social and rights models of disabilities. The closest the CRPD approaches a definition of disability is in paragraph (e) of the preamble which reads:

Disability...results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

This position is echoed in Article 1:

Persons with disabilities include those who have long-term physical, mental intellectual or sensory impairments which in interaction with various barriers may hinder their full and active participation in society on an equal basis with others.

Series (2020ICI) maintained that the CRPD settled on an open-ended description rather than a definition of the treaty's target population, whereas Mladenov (2012a) suggested it was a tentative definition of disability. However, he pointed out that tension existed in translating the English version into other languages as differentiating between disability and impairment presents challenges. States Parties were also challenged by their historical use of impairment to categorise eligibility of government support services. An Australian example is the continued use of impairment by all jurisdictions as a defining variable and eligibility criterion for assistance with education and other disability support programs such as the National Disability Insurance Scheme (NDIS). This scheme was inaugurated in 2013 following an inquiry into disability care and support by the Australian Productivity Commission (2011) which recommended an individual funding model to replace block grants to support agencies.

Interestingly, the wording of Article 1 corresponds closely with the spirit of the World Health Organisation (WHO) (2001) International Classification of Functioning Disability and Health (ICF), which is based upon a biopsychological model of disability one of the aims of which was to integrate the medical and social models of disability. The

ICF conceptualises a person's functioning as an interaction between a person's health conditions, environmental factors, and personal factors.

In addition to his earlier comment, Mladenov (2012a) also highlighted language difficulties with the term “independent living” in the context of Article 19. For example, in Bulgarian language the term is translated back to English as “self-standing” or “autonomous” which does not capture the concept of “independent living” from the perception of the Independent living philosophy (Morris, 2004). Language issues continue to be problematic in the way various member states interpret aspects of their conformity with specific articles.

Social or Rights Model of Disability?

There is ongoing debate concerning the actual role the social model of disability played in the discussions of the Ad Hoc Committee (AHC) in its formulation of the final CRPD proposal to the General Assembly, in comparison to the human rights model. For instance, Kayess and French (2008, p.7) suggested it played an “enormous influence” over the treaty and Traustadottir (2009, p. 3) portrayed it as providing “the knowledge base...which informed” the CRPD. Degener (2017) commented that, as the “motto of the international disability movement...it served as a powerful tool to demand legal reform” (Degener, 2017, p.14). However, she also argued that the social model was replaced by the human rights model which serves as the basis of the implementation of the CRPD. In the lead up to the CRPD, Degener and Quinn (2002) edited *Human Rights and Disability* which was published by the United Nations. They asserted that, “The human rights model focuses on the inherent dignity of the human being.... It places the individual center stage on all decisions affecting him/her and most importantly locates the main problem outside the person and in society” (Degener & Quinn, 2002, p.14). It appears that, in effect, their position on the locus of the disability still rested to a large extent on the social model.

The force of the legal aspects of the human rights model became the most evident in the implementation stage of the CRPD through the establishment of the CRPD Committee which was charged with the monitoring of reports submitted by States members, as noted above by Mladenov (2012a). Nevertheless, Degener (2017) put forward six propositions which asserted quite strongly that there were significant differences between the social and human rights models of disability. However, she did conclude that the human rights model did build on the social model but develops it further.

On the other hand, Lawson and Beckett (2021) strongly contested this approach which they termed the “improvement

thesis”. Instead, they have argued for the “complementary thesis” whereby neither can be seen as an improvement on the other, where their contributions are “complementary and symbiotic” (Lawson & Beckett, 2021, p.350). They also took issue with Degener’s (2017) assertion that the CRPD is a codification of the human rights model of disability. Their searches of the online records of the AHC did not reveal any mention of the term “human rights model.” However, Bickenbach (2016) questioned the rhetoric that it was the social model which animated the convention, referring to it as the “social model fetish” (Bickenbach, 2016, p.116). Further, he warned that the debate was creating an ideological obstacle to fulfilling the promise of the CRPD, largely by advocacy groups. He also suggested that the WHO’s ICF better captured the conception of disability as being “...the outcome of complex interactions between features of a person’s physical and psychological condition and the physical, human-built, sociocultural, attitudinal and political environment” (Bickenbach, 2016, p.116). As noted above the ICF was formulated as a bridge between the medical and social models of disability.

The minority model of disability developed in the 1970s and early 1980s emphasised that disability was located in the environment rather than in the person (Badetti, 2020; Clapton, 2009; Mitchell & Snyder, 2013), paralleling both the WHO (1980) International Classification of Impairments, Disabilities and Handicaps (ICIDH) and the ICF. It also supported a rights-based approach arguing that people with disabilities had the right to full citizenship and equal access to the same extent as people without disabilities.

Another point of contention is the assertion that the social model does not acknowledge the role of impairment on the grounds that it sees disability entirely external to the person. Importantly, Oliver (2004) did point out that the social model “does not ignore questions and concerns relating to impairment and/or the importance of medical and therapeutic treatments (Oliver, 2004, p. 21).” He suggested that the pain and suffering because of impairments was mainly due to the paucity of medical and other health services for people with disabilities.

A significant feature of the human rights model, especially evidenced in the deliberations of the AHC (United Nations Department of Economic and Social Affairs Disability) and the subsequent establishment of the CRPD Committee (United Nations Human Rights Office of High Commissioner, 2008), is its juridical approach which leaves it open to the accusation that the voices of people with disabilities, particularly those with intellectual disabilities, are not being heard. For instance, the States Parties’ reports to the Committee are from governments and not from the people with disabilities. In many cases advocacy bodies do comment upon the reports often highlighting perceived errors and non-compliance issues relevant to the spirit of the Articles. Nevertheless, it is States Parties’

individual government disability policies which in effect determine the extent to which the articles of the CRPD are implemented.

For instance, Clapton (2011) suggested that the disability rights movement has shifted the socio-political identities of people with disabilities from being seen as “... objects of the medical discourse, to subjects of the political discourse. ... Within the liberal state, there is movement of liberation from welfare recipients to a citizen; and hence is also indicative of the shift from exclusion to belonging” (Clapton, 2011, p.76).

This sentiment was strongly echoed by Mladenov (2012a) who posited that the “paradigm shift” is best understood through the phenomenological notion of “being-in-the-world,” a concept developed by Heidegger (1962). Mladenov suggested that the new understanding of disabled people’s “way of being” as subjects of rights rather than as object of charity, treatment, and protection was clearly informed by an emphasis on “individual autonomy,” highlighting their agency. This approach he suggested would be a more fruitful way of understanding the CRPD’s meaning and significance. Series (2020) also noted in the context of the conflicting ongoing application of the “old” paradigm of disability that “...this paradigm shift is far from achieved” (Series, 2020, p.83).

The agency of people with disabilities and especially those with intellectual disabilities is often compromised in the juridical environment of the human rights approach of the CRPD and its monitoring. There is a need, as Mladenov (2012a) has suggested, for a greater participation by disabled people’s collectives in discussions of the extra-juridical dimensions of the Convention’s meanings.

It is a moot point as to whether there is any value in pursuing the debate on the merits of either the social or disability rights models especially in terms of the outcomes being achieved from the CRPD. It is salutary to understand that the Convention did not add any new rights specific to people with disability. It simply attempted to counter the long historical transgressions of basic human rights being experienced by persons with disabilities. As noted, those strongly advocating a legalistically styled rights model of disability run the risk of limiting the agency of the people which the Convention is meant to protect. With its focus on individualism, there is a danger that the widespread advance of neoliberal policies by States members may subvert the genuine realisation of those rights the Convention seeks to achieve.

Threats to Implementation and a Realisation of Outcomes

There has been ongoing commentary on forces which are limiting the full realisation of the human rights of persons with disabilities (Clapton, 2011; Di Rita et al., 2008; Harris et al., 2014; Mladenov, 2015; Parmenter, 2014;

Reinders, 2008a, 2008b, 2016). It is suggested that the traditional welfare system in both low-income and high-income countries has been captured within a neoliberal market economy. Economic rationalist policies are based on the principle of “utility maximisation” where persons can use their resources to achieve their highest level of satisfaction. At the same time, they are free to choose how to use their resources free of interference by governments.

The market economy is driven by the principle of utilitarian individualism which is recognised as the hallmark of neoliberal economic philosophy. Paradoxically, several of the current disability advocacy policies and the general philosophical principles of person-centredness, self-determination, independence, choice, empowerment, and more control over one’s life do appear to resonate with the principles of the market economy. However, the emphasis upon individualism and independence can be a threat to vulnerable people especially those with intellectual disabilities whose dependence can be seen as a moral threat to their standing in comparison to that of other human beings (Edwards, 1997). Nevertheless, interdependence is the essential hallmark of the general human condition wherein communities can provide mutual support, a position noted by Mladenov (2012b) who argued for a collectivist rather than an individualistic approach to disability equality. Robertson et al. (2006) in a United Kingdom longitudinal study of the impact of a person-centred approach found only a modest impact on the areas of social networks, contact with family, contact with friends, community-based activities, scheduled day activities, and choice.

In an Australian study of family support networks, Hillman et al. (2012) found strong support from family members, service providers, and the general community for the CRPD and its promotion of the rights of people with a disability in exercising choice, participation, inclusion, and equality. Significantly, however, the findings, highlighted the difficulties in ensuring that a simplistic interpretation of rights is not used to excuse failure to provide adequate support to people with an intellectual disability, especially those with high support needs. One of the drawbacks of individualised disability support packages, especially within the Australian context, has been the failure of governments to simultaneously build and/or enhance community capacity which is then able to support the needs of all people who are marginalised by environmental and/or attitudinal barriers.

Both Mladenov (2015) and Parker Harris et al. (2014) have been highly critical of the impact neoliberal policies on the delivery of government funded support programs. For instance, in relation to paid employment policies, they have highlighted the strong emphasis upon personal responsibility and economic self-sufficiency, both hallmarks of neoliberal principles.

In addition to the impact of neoliberal ideology, Reinders (2008a) in his analysis of the transformation of human services posited two additional factors which are behind the process of turning the social welfare sector into being parts of the service economy. These are the strategy of New Public Management (NPM) and the culture of managerialism. In particular, he was critical of the way the roles and functions of professional disability support workers have been challenged by these factors. He suggested that neoliberalism does not recognise “need”, because it is aimed at transforming “need” into “choice,” and in effect has shifted in the balance of power from support workers to the person they are supporting.

However, in the case of many people with intellectual disabilities, a sensitive application of the principles of person-centred planning by a trained professional person will support persons in making their informed choices about those aspects of their life they value. For instance, it was the quality of the training of professionals which recently led the Australian Royal Commission recent Report on Abuse, Neglect and Exploitation of People with Disability (Australian Government, 2022) to make twelve recommendations in relation to the education and training of health professionals across Australia, including nurses, dentists, pharmacists, psychologists, and speech pathologists.

Di Rita et al. (2008) have highlighted economic rationalist policies where funding appears to be framed around cost-benefits invoking managerialist principles which focus on the average and procedural supports to manage pluralism and organisational viability. This promotes dependency on organisational patterns of support, “...rather than promoting and developing individual flourishing” (Di Rita et al., p.619). Mittler (2015), in his comprehensive analysis of the implementation of the CRPD articles by States Parties pointed out that the CRPD presented an opportunity “...for fundamental reappraisals of policy and practice by governments. members of professional and voluntary organisations, service planners and providers, the research community and, in the last analysis by society as a whole” (Mittler, 2015, p.79). His analysis revealed several shortcomings which questioned the commitment of States Parties to the spirit of the CRPD:

- a) Limited opportunities given by governments to Disabled Persons Organisations (DPOs) to participate in the development of national action plans,
- b) Implementation plans lacking targets and timelines,
- c) The persistence of charity, welfare, and medical perspectives at the expense of the social model of disability,
- d) A disproportionate emphasis on earlier achievements and future intentions,
- e) Commitment to segregated provision or two-tiered systems described as inclusive in some high-income countries, and
- f) Particular shortcomings in the implementation of

articles on education, employment, independent living, and equality before the law (Mittler, 2015, p.83).

Thus far, the threats to positive outcomes from the CRPD have looked across the broad spectrum of issues related to people with disability in general, especially aspects of disability policies which have subverted those expected outcomes. However, there is an added dimension which needs to be especially examined in respect to people with intellectual disabilities and other related developmental disabilities and their achievement of genuine inclusion, namely, their moral status.

Are Rights Sufficient for People with Intellectual Disabilities to Enjoy Full Inclusion?

The stigmatisation and denial of personhood of people with intellectual disabilities also date back to antiquity from Plato and Aristotle through to Luther and Locke and later as noted above to the Nazi era (Parmenter, 2014). In many respects, this continues to the present day in relation to the reported efforts to reduce the prevalence of Down syndrome (Quinones & Lajka, 2017) and support for assisted dying of people with intellectual disabilities (Stainton, 2019). The assumptions driving these developments are that the lives of people with intellectual disabilities are not lives worth living, based on the wrongful assumption that their quality of life over the lifespan is always poor. It is only in very recent years that laws allowing the sterilisation of girls and women with intellectual disabilities have been overturned. This issue remains problematic when cases are brought before guardianship tribunals. The question of the personhood and moral status of people with intellectual disabilities has been underpinned by a utilitarian bioethical approach which has been challenged by writers including Carlson (2010), Kittay (2010), Langford (2018), Nussbaum (2009, 2011), Reinders (2000), and Sen (1999). A recent report of the UN Human Rights Council Report of the Special Rapporteur on the rights of persons with disabilities also challenged ableist views, pointing out that, "... the lower estimation of the quality of life of persons with disabilities by external observers, including many bioethicists, are caused by unconscious biases towards persons with disabilities" (United Nations Office of High Commissioner, Human Rights, 2019).

Despite the strong advocacy for a full recognition of the personhood and moral status of this population, there remain challenges. Society still has negative attitudes towards people with cognitive limitations. An Australian

attitude study revealed that younger highly educated people and those who had the opportunity to work in disability support roles expressed more positive attitudes towards people with intellectual disabilities than did older people in the general community (Yazbeck et al., 2004). Worldwide, this population has the lowest rate of access to employment in the open labour market (Parmenter, 2011). In 2012, in Australia, only 39% of people with intellectual disability were in the labour force. This compares to 55% of people with other disabilities and 83% of people without disability in the labour force. Additionally, only 12% of people with an intellectual disability were employed full-time compared to 32% of people with other disabilities (Australian Bureau of Statistics (ABS), 2012; Thoresen et al., 2018; Wilson & Campaign, 2020). These data included people working in segregated Australian Disability Enterprises (ADE) which generally do not pay award wages.

In a comprehensive review of the literature Verdonschot et al. (2009) found the following: (a) the average number of persons in their social network was 3.1, one of which was a paid support worker, (b) they are 3–4 times less employed than nondisabled peers, (c) they were less likely to be employed competitively and were more likely to work in sheltered workshops or segregated settings than those with other disabilities, (d) they were less likely to be involved in community groups, (e) leisure activities were mostly solitary and passive in nature, and (f) they were generally accompanied to an activity by support staff.

The other significant areas where human rights initiatives appear to be failing people with disabilities in general and especially people with intellectual disabilities relate to abuse. Both international and national studies have revealed the various forms of abuse that have impacted on people with disabilities (Centre of Research Excellence in Disability and Health, (2021); Didi et al., 2016; Hughes et al., 2012). People with intellectual disabilities can be at higher risk because of communication difficulties and their tendency towards acquiescence with others they view as being in authority.

Questions have been raised whether the reliance upon the moral status provides people with intellectual disabilities affords them protection from harm. For instance, Silvers (2012) suggested that "Appeals to moral status do not settle debates about whether there are obligations to provide protection and support for individuals with disabilities, because the idea of moral status is as contentious as the disagreements it is invoked to resolve" (Silvers, 2012, p.1014). On the other hand, Reinders (2000) offered an alternative to what he has termed "the narrow conception of morality". He suggested that:

...dependent others are accepted because their lives are placed in our hands. We can reject their existence and consider their lives are not worth living. We can leave them to be taken care of by their families and grant them the right

to be sovereign of their own lives. But we can also accept responsibility for the fact they are part of the web of social relationships that constitute our moral world (Reinders, 2000, p. 153).

However, returning to the essential question of the paper, are rights sufficient to ensure the full inclusion of people with intellectual disabilities? Inclusion can be a nebulous concept open to many meanings and interpretations. Clapton (2009) offered a range of options based on a metaphorical “quilt” as a framework to examine various perspectives of inclusion/exclusion, one of which is “ethical inclusion,” referring to it as “ideal inclusion.” This is manifested in the private arena of relationships of acceptance where the emphasis is not upon independence but upon interdependence, mutuality, and flexibility, a view which accommodates difference and redefines moral personhood.

Nirje (1985) often cited as the “father of the normalisation principle” echoed Reinders’ (2000) proposition:

Laws and legislative work cannot provide total answers to problem solving and proper actions with regards to realization of human rights. These can only come into existence in the full cultural and human context. Such problems are not only practical, but also ethical (Nirje, 1985, p. 65).

Reinders (2008b) pointed out that dependency for people with intellectual disabilities is the *conditio sine quo non* for their physical, mental, and spiritual well-being. The challenge, then, is how do we create environments where the interdependence of individuals is a central feature and where individuals perceive their identity and conceptualization of self in the context of a mutually dependent society? It is suggested that reciprocal relationships with people in your community go to the very heart of the definition of true and effective inclusion. Reinders’ (1999) observation that “People can be forced to comply, but they cannot be forced to care” (p. 23) is apposite to this discussion. In a study which explored the concept of loneliness with a sample of people with intellectual disabilities, McVilly et al. (2006) found that loneliness was a significant feature of their lives. They also found, based on the comments of the current participants, “...that personal networks are most effective in meeting people’s social and emotional needs if they include opportunities for relationships that involve people with and without intellectual disability” (McVilly et al., 2006, p. 200).

In assessing a country’s compliance to the articles of the Convention, the CRPD Committee generally takes the more juridical approach rather than asking the question of whether the Convention is contributing to an increase in well-being, happiness, and overall quality of life of people with disabilities. In this respect, there has been some promising research developments underway to link various articles of the CRPD to domains of quality of life (Gomez et al., 2020; Lombardi et al., 2019; Morán et al., 2023; Verdugo et al., 2012). Several countries are now

following the lead of the small Himalayan nation, Bhutan, which established a Gross National Happiness Commission in 1972 to monitor changes in the nation’s happiness (Sachs, 2011). Likewise, Sen’s (1999) development of the capabilities concept influenced the development of the Human Development Index by the United Nations. In 2004 The Organisation for Economic and Community Development (OECD) launched a Global Project on Measuring the Progress of Societies and in 2011, its launch of Better Life Initiatives (Organization for Economic and Community Development, OECD, 2011). Both the United Kingdom and the European Union have appointed ministers of state for happiness and the New Zealand finance minister launched a “wellness budget” in his 2019 budget.

McCallum (2020), in his capacity as a special advisor to the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, presented a research report on the level of Australia’s compliance to the articles of the CRPD. It is noteworthy to observe that Australia was one of the first countries to ratify the Convention and accede to the Optional Protocol which provides a mechanism for individuals to complain directly to the CRPD Committee that their rights have been violated. McCallum pointed out that Australia, as a wealthy country, should be held to a high standard. Nevertheless, after a decade of its ratification of the CRPD, there remained many articles that had not been adopted into Australian law. In addition, the research showed that there were still too many Australians with a disability who experienced discrimination, disadvantage, and violation of human rights especially among its First Nations peoples. The report noted that throughout history people with cognitive, psychosocial, and sensory disabilities have especially suffered from both the unequal and discriminatory application of the law.

Many State Parties, including Australia, face a potential clash between political and civil rights and those deemed to be economic, social, and cultural rights. It is useful to observe that Article 4(2) of the CRPD provides that while State Parties may work towards the realisation of economic, social, and cultural rights; political and civil rights must be granted immediately by ratifying countries. The McCallum report noted, however, that there is a grey area between aspects of the divergence between civil rights and economic rights. These issues reflect the difficulties people with disabilities in general may have in navigating and understanding the complexity of the rights approach in the everyday aspects of their lives. This report’s forensic examination of Australia’s compliance with several of the CRPD articles relevant to the Royal Commission’s terms of reference has revealed that Australia has a long way to go in meeting its obligations under the treaty it ratified.

Tarulli et al. (2016, p.56) observed that “... the CRPD is heralded as a paradigm shift in attitude and practice”,

but it is questionable to what effect this shift is having in the actual lives of people with intellectual disabilities. They are increasingly speaking out, generally in policy forums, but at the practical level are they being listened to by the general community in everyday situations? With integrated employment presence being limited to the few, and despite more access to community living options are they “in” the community, but are not yet “of” it? This question resonates with Mladenov’s (2012a) phenomenological proposition noted above of people with disabilities “being in the world.” In the light of the threats and barriers to the full realisation of the spirit of the CRPD and its promise to people with disabilities, we need to explore an alternative pathway.

The Way Forward: Building an Ethical Community

We need to find an alternative approach which may help achieve full inclusion of people with intellectual disabilities, while at the same time acknowledging the important role the CRPD plays. O’Cinneide (2009) noted that:

The vision of rights embedded in the Convention is thus based upon the recognition that individuals with disabilities are not self-sufficient monist entities, but rather depend upon collective social action to make provision for their basic rights (O’Cinneide, 2009, p. 164).

The eminent psychologist Sarason (1974) introduced the concept of “psychological sense of community” proposing that it become the conceptual centre for the psychology of community, asserting that psychological sense of community “is one of the major bases for self-definition” (Sarason, 1974, p. 157). He further explained his conception as “... the sense that one is part of a readily available, mutually supportive network of relationships upon which one could depend and as a result of which one did not experience sustained feelings of loneliness” (cited by Schwartz, 1992, pp.109–110). This proposition resonates with what Sachs (1988) referred to as the “moral space” of a community setting and also with the notion of collective social action proposed by O’Cinneide (2009).

It is this spirit of co-dependence which is captured in Dokecki’s (1992) concept of an “ethical community.” He argued that “... we should work toward an ethical conception of community, which establishes that all persons are fundamentally equal as human beings” (Dokecki, 1992, p. 40). A key element in the concept of an ethical community it is suggested is the proposition of “caring” raised by Reinders (1999, 2000) above. For instance, Schwartz (1992) suggested that:

The correct tool for caring...arises from an understanding of a contrasting world view which we can term ‘associational’. It recognises that caring always arises in a cultural setting, and

that it always is something that happens between people. It understands that the psychological sense of community is the key concept which lets us know if a cultural context exists in which caring is likely to arise (Schwartz, 1992, p. 113).

In respect to earlier comments concerning the juridical nature of the CRPD and the dominance of the neoliberal forces in the formulation of disability policy and practice, Schwartz’s (1992) contrast between the professional/bureaucratic and the associational world views in the context of how public policy can either support or suppress the notion of a psychological community is especially pertinent to the ethical community proposition.

Turnbull (1998) pointed out that each member of a community must recognize that all are vulnerable in some aspects of their lives. As a first step, therefore, the ethical community must recognize what Turnbull eloquently suggested as “a mutuality of need and reciprocity of vulnerability” (cited Parmenter, 2001, p. 289). An ethical community would also recognise that all persons are equal as human beings, and all persons are dependent on others in a metaphorically deep way (Edwards, 1997). The development of an ethical community would be an antidote to one of the most significant barriers to the implementation of the spirit and reality of the CRPD, namely, the growth of individualism and the market-based economies which fail to recognise the important role communality has played in the history of the human species.

Whilst the quality of life and social inclusion of people with intellectual disabilities may appear to depend upon external socio-political-economic forces beyond their control, their level of acceptance as fellow human beings and citizens can be influenced by the humanity and compassion of the general community. Therefore, it is imperative for the achievement of full inclusion of people with intellectual disabilities that there is an engagement with the wider community in its journey to quality of life and happiness. We have possibly been too focused on the needs of people with intellectual disabilities in isolation from those of the wider community, and in so doing have failed to recognise the reciprocity aspect of the inclusion process. Have we been sufficiently strategic in our thinking, our policies, or our actions? In conclusion, the prophetic words of poet John Donne are apposite in the context of the case for an ethical community: “No man (sic) is an island, entire of itself. Every man (sic) is a piece of the continent, A part of the main.” (John Donne, Meditation XV11, cited by Abella, 2017).

Funding Open Access funding enabled and organized by CAUL and its Member Institutions

Declarations

Competing Interests The authors declare no competing interests.

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