



## **Disability Human Rights Clinic**

### **The United Nations Convention on the Rights of Persons with Disabilities and the right to support**

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This report is the outcome of a project undertaken during the Disability Human Rights Clinic's second semester in 2016.

The clinic was co-ordinated by Yvette Maker and Dr Annegret Kaempf (under the leadership of Dr Anna Arstein-Kerslake) and is one of the subjects in Melbourne Law School's Public Interest Law Initiative, which offers experiential learning to Juris Doctor students.

Students in the clinic learn to apply a human rights framework to legal analysis on projects that target issues concerning rights violations experienced by persons with a disability.



**Melbourne Law School**

## I INTRODUCTION

1. The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) sets out in detail how recognised international human rights law should be implemented in the context of persons with disabilities. Persons with disabilities continue to experience human rights shortcomings, in particular due to lack of funding and inappropriate policies relating to welfare.<sup>1</sup> Historically, disability has been treated as an issue of welfare and charity; this approach has been criticised for being paternalistic and failing to encourage ‘independence, social integration and participation in the life of the community’.<sup>2</sup> Welfare approaches traditionally focused on providing institutional forms of care to persons with disabilities which kept them in a state of dependency, rather than providing them with support and enabling their participation in society.<sup>3</sup> This has been an ongoing barrier for persons with disabilities to participate as equal persons in all aspects of life. This is because traditional approaches have excluded them from engaging in decision making about their personal affairs and from society more generally.<sup>4</sup> The CRPD moves away from this welfare approach towards a human rights approach that recognises a broad duty to provide support in achieving full equality of rights for persons with disabilities.<sup>5</sup> The development of the human rights approach is discussed further below.
2. The purpose of this paper is to demonstrate the obligation on States to provide support as a principle in international human rights law. Part II of this paper will outline the development of the understanding of disability, and the movement towards a human rights approach to disability. The CRPD contemplates support, reasonable accommodation and accessibility as measures necessary to achieving full enjoyment of human rights for persons with disabilities. Part III will distinguish between support, reasonable accommodation and accessibility to demonstrate why support is essential in providing for full realisation of human rights. Part IV will introduce the arguments in the subsequent two parts and highlight the nature of support as both a cross-cutting obligation

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<sup>1</sup> World Health Organization, *World Report on Disability* (2011) 139.

<sup>2</sup> Andrew Power, Janet E. Lord and Allison S. DeFranco, *Active Citizenship and Disability: Implementing the Personalisation of Support* (Cambridge University Press, 2013) 3.

<sup>3</sup> *Ibid* 6.

<sup>4</sup> *Ibid* 7.

<sup>5</sup> Rosemary Kayess and Phillip French, ‘Out of the Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* 1, 3.

and a precondition to human rights. Part V will discuss how the notion of support is explicitly included in the CRPD,<sup>6</sup> as well as being implicit in some previous international human rights instruments. Part VI will establish that the notion of support can be derived from human rights principles. Therefore, the State obligation to provide support is entrenched within international human rights law.

## II CHANGING APPROACHES TO DISABILITY

3. Disability is an evolving concept. The prevailing medical model has been challenged by the social model and the human rights approach.
4. The medical model treats disability as a problem of the individual's impairments which hinders their full and effective participation in society.<sup>7</sup> This medicalisation of people's impairments promotes assimilation and leads to solutions focusing on treatment, cure, care and institutionalisation rather than active engagement in society.<sup>8</sup> By viewing the impairment as a problem to be treated, this approach results in policy and practice that oppresses and excludes the individual.<sup>9</sup>
5. In contrast, the social model locates disability in the interaction between the social environment and impairment.<sup>10</sup> It focuses on addressing the social, physical and attitudinal environmental barriers to equal participation and inclusion of persons with disabilities.<sup>11</sup> The 'social environment' is the reciprocal relationship between the physical environment and human behaviour.<sup>12</sup> The social model shifts the focus away from a person's impairment and puts responsibility on society to eliminate barriers faced by persons with disabilities.<sup>13</sup> Therefore, this justifies the obligation on the State to remove

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<sup>6</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008) art 4(1)(e) Preamble para (f); arts 4(1), 12, 13, 16, 19, 20, 23, 24, 26, 29, 30 ('CRPD').

<sup>7</sup> Kayess and French, above n 5, 5.

<sup>8</sup> Power, Lord and DeFranco, above n 2, 7.

<sup>9</sup> Kayess and French, above n 5, 6.

<sup>10</sup> Jenny Morris, 'Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights' (2001) 16(4) *Hypatia* 1, 9; Kayess and French, above n 5, 6.

<sup>11</sup> Morris, above n 10, 9; Kayess and French, above n 5, 6.

<sup>12</sup> Bruce A. Thyer, Catherine N. Dulmus and Karen M. Sowers, *Human Behavior in the Social Environment: Theories for Social Work Practice* (Wiley, 1<sup>st</sup> ed, 2012) 8.

<sup>13</sup> Morris, above n 10, 3.

these barriers.<sup>14</sup> In this paper, consistent with the CRPD, disability refers to the barriers imposed on persons with disabilities.<sup>15</sup>

6. Impairment is used as a value free term that captures the features and attributes of the body.<sup>16</sup> For example, an impairment would be a person not being able to walk, but a disability would be a person's inability to travel to and from work or other activities because there is no accessible public transport.<sup>17</sup> Some critical disability studies scholars have highlighted the reality of impairment and its impact on the experience of persons with disabilities.<sup>18</sup> For example, Jenny Morris emphasises that the experience of living with impairment should not be ignored.<sup>19</sup> Morris expresses concern that if persons with disabilities are not given an opportunity to share their experiences, States will continue to ignore their rights and provide support services in ways that disempower persons with disabilities.<sup>20</sup> Difference should not be denied but rather used to facilitate equal access to human and civil rights.<sup>21</sup> Persons with disabilities are entitled to the same human rights as other people; however, in many situations these rights cannot be realised without further actions being taken to ensure equal access.<sup>22</sup> Therefore, to achieve the full and effective participation of persons with disabilities on an equal basis with others in society, it will often be insufficient to simply alter the physical environment or remove other impediments to the exercise of rights, and tailored support measures and accommodation to the situation of persons with disabilities may be required.
7. The CRPD is said to codify the social model, but also extends that model by offering a human rights approach to disability.<sup>23</sup> The social model of disability has been criticised for ignoring the effect of impairment for disabled persons (such as pain and shorter life expectancy), and treating all impairment the same.<sup>24</sup> The human rights approach to disability varies from the social model in that the focus is on achieving enjoyment of

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<sup>14</sup> *CRPD*, 999 UNTS 3, art 4(1)(e) ('*CRPD*').

<sup>15</sup> *CRPD*, 999 UNTS 3, Preamble para (e).

<sup>16</sup> Morris, above n 10, 3.

<sup>17</sup> *Ibid.*

<sup>18</sup> Kayess and French, above n 5, 33-34.

<sup>19</sup> Morris, above n 10, 9-11.

<sup>20</sup> *Ibid.*

<sup>21</sup> *Ibid* 9-12.

<sup>22</sup> *Ibid* 11-12.

<sup>23</sup> Theresia Degener, 'Disability in the Human Rights Context' (2016) 5(3) *Laws* 35, 2-3.

<sup>24</sup> *Ibid* 7.

human rights on an equal basis with others.<sup>25</sup> It only considers impairments insofar as it is necessary to understand what measures are required for persons with disabilities to access human rights.<sup>26</sup> This approach places the individual at the centre of all decisions affecting him or her.<sup>27</sup> The individual is the subject of rights and not merely an object to be controlled by the state.<sup>28</sup>

8. As with the social model, the human rights model locates disability outside of the person and therefore as created by the failure of States to consider the lived experience of persons with disabilities and facilitate their equal participation in society.<sup>29</sup> To achieve equal recognition of human rights, States have an obligation to eliminate all socially created barriers.<sup>30</sup> The advantage of the human rights model is that it acknowledges the relevance of the impairment while maintaining the focus on overcoming the barriers. Respect for diversity and difference is an important part of human rights law.<sup>31</sup> Article 3(d) of the CRPD refers to ‘respect for difference and acceptance of persons with disabilities as part of human diversity and humanity’.<sup>32</sup> Theresia Degener states that ‘the diversity principle of Article 3 CRPD is a valuable contribution to human rights theory in that it clarifies that impairment is not to be regarded as a deficit or as a factor that can be detrimental to human dignity’.<sup>33</sup>
9. The CRPD rejects the medical model and its treatment of persons with disabilities as ‘objects of charity, medical treatment and social protection’<sup>34</sup> and instead embodies a view of disabled persons as ‘subjects of rights, able to claim those rights as active

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<sup>25</sup> Catalina Devandas-Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities*, 28<sup>th</sup> sess, UN Doc A/HRC/28/58 (2 February 2015) 3-5.

<sup>26</sup> Gerard Quinn and Theresia Degener, *The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability*, HR/PUB/02/1 (2002) 14.

<sup>27</sup> *Ibid.*

<sup>28</sup> *Ibid* 13-14.

<sup>29</sup> *Ibid* 14.

<sup>30</sup> *Ibid.*

<sup>31</sup> Degener, above n 23, 7.

<sup>32</sup> *CRPD*, 999 UNTS 3, art 3(d).

<sup>33</sup> Degener, above n 23, 8.

<sup>34</sup> Kayess and French, above n 5, 3; Statement by Louise Arbour, UN High Commissioner for Human Rights to the Resumed 8th Session of the Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities (5 December 2006) <<http://www.un.org/esa/socdev/enable/rights/ahc8hrcmsg.htm>> .

members of society’.<sup>35</sup> The obligation for States to respect human rights has long been established prior to the CRPD.<sup>36</sup> However, the CRPD combines human rights principles with the social model to elaborate on what is required to realise human rights for persons with disabilities.<sup>37</sup> The CRPD defines disability as a product of the interaction of persons with impairments with various barriers which limit their full and effective participation on an equal basis within society.<sup>38</sup> Some fundamental human rights principles (that is, those that are essential goals of human rights) are also incorporated within the Preamble paragraphs (a), (c), (h), (i), (j), (k), (m), (n) and (o), and in particular in Article 3 which sets out ‘general principles’. For example, paragraph (a) acknowledges the principles of inherent dignity and equal rights as foundations of ‘freedom, justice and peace in the world’.<sup>39</sup> Paragraph (h) recognises that discrimination is violation of the inherent dignity of the person.<sup>40</sup>

### **III DEFINING ACCESSIBILITY, REASONABLE ACCOMMODATION AND SUPPORT**

10. Under the CRPD, States have a general obligation to take all appropriate measures to ensure the full realisation of all human rights and fundamental freedoms for persons with disabilities.<sup>41</sup> These measures include but are not limited to accessibility,<sup>42</sup> reasonable accommodation,<sup>43</sup> and support and assistance.<sup>44</sup> Although these are related concepts, this paper distinguishes them to highlight that states have distinct and separate obligations to provide accessibility, reasonable accommodation and support, each of which is aimed at achieving full realisation of the rights of persons with disabilities.

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<sup>35</sup> Kayess and French, above n 5, 3; Statement by Louise Arbour, UN High Commissioner for Human Rights to the Resumed 8th Session of the Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities (5 December 2006) <<http://www.un.org/esa/socdev/enable/rights/ahc8hrcmsg.htm>>.

<sup>36</sup> Rhona K.M. Smith, *Textbook on International Human Rights* (Oxford University Press, 4<sup>th</sup> ed, 2014) 5, 7.

<sup>37</sup> *CRPD*, 999 UNTS 3, art 4.

<sup>38</sup> Kayess and French, above n 5, 24; *CRPD*, 999 UNTS 3, art 1.

<sup>39</sup> *CRPD*, 999 UNTS 3, Preamble para (a).

<sup>40</sup> *CRPD*, 999 UNTS 3, Preamble para (h).

<sup>41</sup> *CRPD*, 999 UNTS 3, art 4.

<sup>42</sup> *CRPD*, 999 UNTS 3, art 9.

<sup>43</sup> *CRPD*, 999 UNTS 3, art 2 (definition “Reasonable Accommodation”).

<sup>44</sup> *CRPD*, 999 UNTS 3, Preamble para (f); arts 4(1), 12, 13, 16, 19, 20, 23, 24, 26, 29, 30.

## A *Accessibility*

11. The CRPD reaffirms the right to access for persons with disabilities and requires States to take appropriate measures to:

ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and rural areas.<sup>45</sup>

12. In the case of *Nyusti and Takács v Hungary*, the Committee on the Rights of Persons with Disabilities stated that all services open to the public, including those provided by private entities, must be accessible in accordance with Article 9 of CRPD.<sup>46</sup> States must develop minimum standards for accessibility and monitor the implementation of these standards.<sup>47</sup>

13. This right is applicable to all persons, and other human rights instruments have previously addressed access-related rights. For example, the *International Covenant on Civil and Political Rights* (ICCPR) recognises that all persons have the right to access public services.<sup>48</sup> Similarly, the *International Convention on Elimination of All Forms of Racial Discrimination* provides that everyone has the right to have access to all places intended to be used by the public, for example transport, cafes and parks.<sup>49</sup> The right was explicitly included in the CRPD in recognition of the fact that persons with disabilities are frequently prevented from enjoying basic human rights because the built environment, transportation and information formats remain inaccessible to them.<sup>50</sup>

14. The CRPD recognises that accessibility is a precondition to the enjoyment of other civil, political, economic, social and cultural rights by persons with disabilities, including the

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<sup>45</sup> CRPD, 999 UNTS 3, art 9.

<sup>46</sup> Committee on the Rights of Persons with Disabilities, *Communication No. 1/2010*, 9th sess, CRPD/C/9/D/1/2010 (15-19 April 2013) [9.4], [10] (*'Nyusti, Takács, & Fazekas v. Hungary'*).

<sup>47</sup> *Ibid.*

<sup>48</sup> *Universal Declaration on Human Rights*, GA Res 217A (III), UN GAOR, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) (*'UDHR'*); *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) (*'ICCPR'*);

<sup>49</sup> *International Convention on Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969) art 5(f).

<sup>50</sup> World Health Organization, *World Report on Disability* (2011) 4, 6.

right to independent living and the right to participation in all aspects of life.<sup>51</sup> For example, a wheelchair user is not able to participate in employment if the principal place of business is located in an inaccessible building. Therefore, it is often inaccessible environments and information that produce disability for persons with impairments.

15. Inadequate access to physical environments, information and communication technologies amounts to discrimination.<sup>52</sup> States have an obligation not to discriminate against persons with disabilities.<sup>53</sup> Consequently, States have an obligation to provide accessibility before receiving individual requests to use particular spaces, information or services.

### **B Reasonable Accommodation**

16. Reasonable accommodation is another type of measure that promotes enjoyment of human rights and eliminates discrimination. As with accessibility measures, reasonable accommodation seeks to improve access.<sup>54</sup> These measures may be implemented where there is a failure to achieve accessibility for an individual. For example, people with different impairments might have different accessibility requirements: visually impaired people might prefer steps with defined curbs and indented paving, while this may impede wheelchair users who require ramps and smooth surfaces.<sup>55</sup> Additionally, people with the same impairments could also have different access requirements: some visually impaired people might be able to read Braille while others might require access to audio files. A library that has thousands of books might not be able to afford to make the whole catalogue accessible in different formats, but could make arrangements to make some books available on demand.<sup>56</sup> This highlights that accessibility measures may not be the most practical and efficient way to eliminate all environmental barriers and sometimes measures tailored to the individual may be more appropriate.

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<sup>51</sup> CRPD, 999 UNTS 3, art 9; Committee on the Rights of Persons with Disabilities, *General Comment No 2: Article 9: Accessibility*, 11<sup>th</sup> sess, CRPD/C/GC/2 (22 May 2014) [1]-[4] ('*General Comment No 2 Accessibility*').

<sup>52</sup> *General Comment No 2 Accessibility*, CRPD/C/GC/2, [23].

<sup>53</sup> CRPD, 999 UNTS 3, art 5.

<sup>54</sup> *General Comment No 2 Accessibility*, CRPD/C/GC/2, [24].

<sup>55</sup> *Ibid.*

<sup>56</sup> *Ibid.*

17. Whereas accessibility is related to improving accessibility for groups of people, the duty to provide reasonable accommodation is related to individuals.<sup>57</sup> While the duty to provide accessibility applies all of the time, regardless of individual requests,<sup>58</sup> the duty to provide reasonable accommodation applies *ex nunc*, when a person needs it, and allows for individual differences or preferences to be taken into account.<sup>59</sup> The CRPD defines reasonable accommodation as:

necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.<sup>60</sup>

18. Reasonable accommodations are a response to inequality and discrimination towards individuals. A failure to afford a person a reasonable accommodation results in discrimination.<sup>61</sup> Reasonable accommodations are crucial in achieving substantive equality for individuals with disabilities by taking the individual's dignity, autonomy and choices into account.<sup>62</sup> However the obligation to reasonably accommodate a person is limited; for example, the CRPD limits the obligation to accommodations 'not imposing a disproportionate or undue burden'.<sup>63</sup> This may limit the extent to which accommodations to overcome inequality are actually available. Similar limitations have been included in the anti-discrimination legislation of many States. In Australia, the *Disability Discrimination Act 1992* (Cth) defines the similar concept of 'reasonable adjustment' as adjustments that should be made unless they impose unjustifiable hardship on the person.<sup>64</sup> The United States has a similar provision dealing with undue hardship.<sup>65</sup> Using the previous example of the library, a well-funded library should be able to accommodate individual requests to provide books in other formats. However, a small library that is run

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<sup>57</sup> *General Comment No 2 Accessibility*, CRPD/C/GC/2, [25].

<sup>58</sup> *General Comment No 2 Accessibility*, CRPD/C/GC/2, [25].

<sup>59</sup> *General Comment No 2 Accessibility*, CRPD/C/GC/2, [26].

<sup>60</sup> CRPD, 999 UNTS 3, art 2 (definition "Reasonable Accommodation").

<sup>61</sup> Gerard Quinn and Anna Arstein-Kerslake, 'Restoring the 'human' in 'human rights': personhood and doctrinal innovation in the UN disability convention' in Conor Gearty and Costas Douzinas (eds), *The Cambridge Companion to Human Rights Law* (Cambridge University Press, 2012) 36, 42.

<sup>62</sup> *General Comment No 2 Accessibility*, CRPD/C/GC/2, [26].

<sup>63</sup> Kayess and French, above n 5, 6.

<sup>64</sup> *Disability Discrimination Act 1992* (Cth) s 3 (definition of "Reasonable Adjustments").

<sup>65</sup> *The Americans with Disabilities Act of 1990*, 42 USC § 12112 (1990).

by volunteers and has limited resources may argue that it would impose a disproportionate or undue burden to accommodate such requests. This demonstrates the limitations of reasonable accommodation.

### **C Support**

19. In spite of these limitations, States have an obligation to promote equal treatment for persons with disabilities, and must provide other support to eliminate disabling barriers. States arguably have an obligation to provide support to ensure that persons with disabilities are able to exercise their rights on an equal basis with others, by virtue of the fact that human rights apply equally to all persons, including persons with disabilities.
20. Support is a broad term that can encompass any number of measures that allow persons with disabilities to enjoy human rights on an equal basis with others.<sup>66</sup> Examples of support include personal assistance, financial support and legal support.<sup>67</sup> According to Raelene West, support can be categorised as and should include both individualised and systematic support.<sup>68</sup> The individual support is tailored to the individual while systematic support is set up by an entity or landscape to provide services such as financial support which may be accessed by the individual when necessary.<sup>69</sup>
21. Without support, persons with disabilities may be forced to rely on care from their families and this can reduce the ability of persons with disabilities and their families to participate in society on an equal basis with others.<sup>70</sup> Disability studies scholars and activists have long argued that care must be replaced with alternative forms of support. This is because care is associated with dependency, burden and deficit,<sup>71</sup> and reinforces the notion that persons with disabilities need to be nurtured and protected. This leads to power imbalances and oppression.<sup>72</sup> The provision of care is more akin to the medical

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<sup>66</sup> World Health Organisation, *World Report on Disability Report* (2011) 137.

<sup>67</sup> *Ibid* 139.

<sup>68</sup> Raelene West, 'What do we mean by support for people with impairment' (Paper presented at Disability Studies Conference, Lancaster University, 7-9 September 2010) 3.

<sup>69</sup> *Ibid*.

<sup>70</sup> Bill Hughes, Linda McKie, Deborah Hopkins and Nick Watson, 'Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care' (2005) 39(2) *Sociology* 259, 261.

<sup>71</sup> West, above n 68, 5; Anita Silvers, 'Reconciling equality to difference: Caring for justice for people with disabilities' (1995) 10(1) *Hypatia* 30.

<sup>72</sup> Jenny Morris, 'Care or empowerment? A disability rights perspective' (1997) 31(1) *Social Policy & Administration* 54; West, above n 68, 6.

model of disability which treats persons with disabilities as objects rather than right holders.

22. In contrast, the concept of support promotes a more balanced and less dependency-based identity, empowering individuals to make choices and have control over how their needs are met and how they exercise their rights.<sup>73</sup> A key way that this choice and control is promoted is through ‘personalisation’, which includes direct funding to persons with disabilities to allow them to make choices on how to manage and select their support services.<sup>74</sup> This personalisation model has the potential to transform the paternalistic and medical model approach of care by empowering the individual to make choices to reflect their life choices.<sup>75</sup>
23. The CRPD explicitly provides for support measures to be implemented in relation to rights captured in the convention.<sup>76</sup> The term ‘support’ is not defined in the CRPD but there are a number of provisions that refer to it throughout the instrument. Article 3 of the CRPD creates a general obligation on States to provide support services which focus on respecting the autonomy and dignity of the individual and ensuring their inclusion within the society.<sup>77</sup> Support measures are explicitly envisaged in a number of other articles, including: Article 9 (accessibility); Article 12 (equal recognition before the law); Article 13 (access to justice); Article 16 (freedom from exploitation, violence and abuse); Article 19 (living independently and being included in the community); Article 20 (personal mobility); Article 23 (respect for home and the family); Article 24 (education); Article 26 (habilitation and rehabilitation); Article 29 (participation in political and public life); and Article 30 (participation in cultural life, recreation and sport). For example, Article 12 requires States to take appropriate measures to provide support to persons with disabilities to exercise their legal capacity.<sup>78</sup> Article 29, provides that States must

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<sup>73</sup> West, above n 68, 7; Kirstein Rummery, ‘A comparative analysis of personalisation: Balancing an ethic of care with user empowerment’ (2011) 5(2) *Ethics and Social Welfare* 138.

<sup>74</sup> Christiane Purcal, Karen R. Fisher and Carmel Laragy, ‘Analysing Choice in Australian Individual Funding Disability Policies’ (2014) 73(1) *Australian Journal of Public Administration* 88, 89.

<sup>75</sup> Helen Dickinson, Catherine Needham and Helen Sullivan, ‘Individual Funding for Disability Support; What are the Implications for Accountability?’ (2014) 73(4) *Australian Journal of Public Administration* 417, 418.

<sup>76</sup> CRPD, 999 UNTS 3, Preamble para (f); arts 4(1), 12, 13, 16, 19, 20, 23, 24, 26, 29, 30.

<sup>77</sup> Power, Lord and DeFranco, above n 2, 27.

<sup>78</sup> CRPD, 999 UNTS 3, art 12(3).

guarantee to persons with disabilities political rights and allows for assistance in voting if necessary.<sup>79</sup>

#### **D Assistance**

24. Assistance is another relevant term that is mentioned in the CRPD. For example, Paragraph (x) of the Preamble to the CRPD recognises the importance of providing ‘necessary protection and assistance’ to persons with disabilities and their families ‘to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities’.<sup>80</sup> The concept of assistance – particularly personal assistance – has also been proposed in the disability studies literature as an alternative to care. This is because it does not imply dependency, and places control with persons with disabilities to, for example, employ a personal assistant to perform certain tasks.<sup>81</sup> In this paper, assistance is assumed to be one specific form of support.

#### **IV SUPPORT AS A PRECONDITION AND CROSS-CUTTING OBLIGATION**

25. Although all international human rights instruments apply equally to persons with disabilities, many of them do not specifically address the human rights situation of persons with disabilities.<sup>82</sup> In these instruments, disability is almost invisible and generally only mentioned when dealing with social security and preventative health policy.<sup>83</sup> However, the absence of express mention of support does not imply that the obligation to provide support does not exist. The next two parts will establish that support is both a precondition to the enjoyment of human rights and a cross-cutting obligation applicable across the rights in the CRPD.<sup>84</sup>

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<sup>79</sup> *CRPD*, 999 UNTS 3, art 29(a)(iii).

<sup>80</sup> Kayess and French, above n 5, 26.

<sup>81</sup> Teppo Kröger, ‘Care research and disability studies: Nothing in common?’ (2009) 29(3) *Critical Social Policy* 398, 405; Nick Watson, Linda McKie, Bill Hughes, Debra Hopkins and Sue Gregory, ‘(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model’ (2004) 38(2) *Sociology* 331, 336; Helen Spandler, ‘Friend or Foe? Towards a Critical Assessment of Direct Payments’ (2004) 24(2) *Critical Social Policy* 187.

<sup>82</sup> Power, Lord and DeFranco, above n 2, 20.

<sup>83</sup> *Ibid.*

<sup>84</sup> *Ibid.* 23.

26. Human rights obligations fall onto States.<sup>85</sup> The human right to support creates a corresponding obligation on the State to provide support. The right and the obligation to provide support are used interchangeably in this paper. This does not imply that there is a freestanding right to support generally. The ‘right to support’ recognised in this paper is linked to specific contexts where the provision of support is necessary to achieve widely recognised human rights.
27. Part V will consider particular rights included in the international human rights instruments, including the International Bill of Rights,<sup>86</sup> the *United Nations Convention on the Rights of the Child* (CRC), the *United Nations Convention on Elimination of Discrimination Against Women* (CEDAW) and the *Draft Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa* (the ‘Draft Protocol’), to highlight that the notion of support that is explicitly contained in the CRPD is implicitly present in previous human rights instruments.
28. Part VI, will demonstrate that support is a precondition to the equal enjoyment of human rights by drawing a link between support and some of the fundamental human rights principles recognised in human rights law. This part will focus on the following fundamental principles of human rights: universality; individual autonomy; non-discrimination and equality; and participation and inclusion.

## V HUMAN RIGHTS INSTRUMENTS

### A Introduction

29. This part involves an analysis of existing international human rights instruments to demonstrate that the obligation to provide support has been implicitly recognised in these instruments in promoting the full realisation of human rights. This is relevant because it illustrates that the notion of support has foundation in a broader context than the CRPD, and is not simply a notion that is limited to the context of disability human rights. It

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<sup>85</sup> Jack Donnelly, *Universal Human Rights in Theory and Practice* (Cornell University Press, 2<sup>nd</sup> edition, 2003) 34.

<sup>86</sup> *Universal Declaration on Human Rights*, GA Res 217A (III), UN GAOR, 3<sup>rd</sup> sess, 183<sup>rd</sup> plen mtg, UN Doc A/810 (10 December 1948) (‘UDHR’); *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) (‘ICCPR’); *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976) (‘ICESCR’).

implies that an obligation to provide support in order to ensure the exercise of human rights is applicable to all persons, not just persons with disabilities. By extension, the CRPD can provide a useful tool for interpreting the obligation of support in all human rights instruments, beyond the context of disability.

30. *The Universal Declaration of Human Rights* (UDHR) recognises that human rights are a common standard to be enjoyed by all people of all nations.<sup>87</sup> This has been highlighted in the discussion of the human rights principle of universality, below. The ICCPR provides that States must provide measures to give effect to the rights recognised in the Covenant.<sup>88</sup> Although there is no definition of measures in the Covenant, it extends to States taking steps to ensure the full realisation of civil and political rights for all citizens. The CRC provides that States must take all measures to ensure that the child is protected against all forms of discrimination.<sup>89</sup> Assistance is one of the measures specifically recognised in the CRC. Article 23 of the CRC recognises that children with disabilities should enjoy a full and decent life, in conditions that ensure the child's active participation in the community. This article also explicitly provides that assistance to children with disabilities shall be designed to ensure a child's effective participation in his or her development, including his or her education, preparation for employment and recreation opportunities.<sup>90</sup> Therefore, it is clear that support and assistance are contemplated in the CRC as measures that may be necessary to achieve enjoyment of rights. Similarly, the CRPD requires States to take necessary measures to ensure that children with disabilities fully enjoy their human rights on an equal basis with other children.<sup>91</sup> As mentioned above, the CRPD is explicit in requiring States to provide support to ensure full realisation of human rights for persons with disabilities, for example, the right to support for children with disabilities in relation to education. This is discussed further below.<sup>92</sup>

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<sup>87</sup> *UDHR*, UN Doc A/810, Preamble.

<sup>88</sup> *ICCPR*, 999 UNTS 171, art 2 (2).

<sup>89</sup> *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 2(2) ('*CRC*').

<sup>90</sup> *CRC*, 1577 UNTS 3, art 23(3).

<sup>91</sup> *CRPD*, 999 UNTS, art 7.

<sup>92</sup> *CRPD*, 999 UNTS, art 24.

31. The following rights are discussed: equal recognition of persons before the law, adequate standard of living and social protection and the right to education.

### ***B Equal Recognition of Persons Before the Law***

32. The right to recognition before the law is a universal right that is indispensable to the exercise of human rights. Article 6 of the UDHR provides that everyone has the right to be recognised as a person before the law. The use of the word ‘everywhere’ emphasises that the right to recognition applies in all circumstances without any exceptions under the international human rights law.<sup>93</sup> This right is mirrored in Article 16 of the ICCPR and other international human rights treaties.<sup>94</sup> The right to equal recognition before the law is a fundamental human right that is recognised, for example, in Article 15 of the CEDAW and Article 26 of the ICCPR.

33. Additionally, Article 12 of the CRPD explicitly states that person with disabilities should be recognised before the law. This highlights that the right to equal realisation of persons before the law is a civil and political right which should be recognised immediately.<sup>95</sup> Therefore, persons with disabilities must be immediately recognised as having legal capacity on an equal basis with others in all areas of life.<sup>96</sup> Legal capacity is important because it allows individuals to exercise their agency in making decisions relating to all spheres of life, including intimate, social and political spheres.<sup>97</sup> To deny an individual the right to legal capacity will have drastic consequences for the person, analogous to his or her ‘civil death’.<sup>98</sup>

34. The right to equal recognition before the law in Article 12 of the CRPD provides that States have an obligation to ensure persons with disabilities have access to the support required for them to exercise their legal capacity. Article 12, paragraph 3 of the CRPD

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<sup>93</sup> Committee on the Rights of Persons with Disabilities, *General Comment No 1: Article 12 Equal Recognition before the law*, CRPD/C/GC/1 (11 April 2014) [5] (‘General Comment No 1: Article 12’).

<sup>94</sup> *International Covenant on the Elimination of All Forms of Discrimination against Women*, opened for signature 3 September 1979, 1249 UNTS 13 (entered into force 18 December 1981) art 12 (‘CEDAW’); *Draft Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa*, opened for signature 25 February 2016, ACHPR 19<sup>th</sup> extraordinary session (not yet in force) art 3 (‘Draft Protocol to African Charter’).

<sup>95</sup> General Comment No 1: Article 12, CRPD/C/GC/1, [30].

<sup>96</sup> General Comment No 1: Article 12, CRPD/C/GC/1, [6]-[10].

<sup>97</sup> Quinn and Arstein-Kerslake, above n 61, 42.

<sup>98</sup> *Ibid* 42-43.

provides for a right to support in the exercise of legal capacity.<sup>99</sup> This is also supported by the fact that States are obliged to replace regimes involving substituted decision-making and replace these with supported decision-making ‘which respects the person’s autonomy, will and preferences’.<sup>100</sup>

35. Additionally, Article 14 of the ICCPR recognises that all persons shall be equal before the courts and tribunals. The ICCPR recognises that in some cases, for justice to be achieved, States must take measures to provide legal assistance to persons who are not able pay for it.<sup>101</sup> Therefore, this article explicitly requires States to provide support to persons who cannot afford legal representation. The requirement to provide legal assistance can be analogised with the State obligation to provide support to persons with disabilities. An example is using supported decision-making to allow persons with disabilities to exercise their legal capacity. In both scenarios, States are providing support to persons to allow for their full realisation of rights.

36. Article 12 of the CRPD recognises that persons with disabilities have the right to equal recognition before the law and States have an obligation to provide support to achieve full realisation of this right.<sup>102</sup> The above discussion illustrates that the basis for this right could be found implicitly in human rights law prior to the existence of the CRPD.

### ***C Adequate Standard of Living and Social Protection***

37. Article 25 of the UDHR provides for ‘the right to a standard of living adequate for the health and well-being’ of an individual and his or her family.<sup>103</sup> This includes provision of necessary goods and services, and a right to security in the event of various potential circumstances, such as disability and sickness, which are beyond the individuals’ control, but which may impact on their ability to access an adequate livelihood.<sup>104</sup> Article 25 also provides that motherhood and childhood are periods in which there is an entitlement to ‘special care and assistance’.<sup>105</sup> States have an obligation, as a last resort, to fulfil

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<sup>99</sup> *CRPD*, 999 UNTS, art 12(3).

<sup>100</sup> General Comment No 1: Article 12, *CRPD/C/GC/1*, [26].

<sup>101</sup> *ICCPR*, 999 UNTS 171, art 14(3)(d).

<sup>102</sup> *CRPD*, 999 UNTS, art 12(3).

<sup>103</sup> *UDHR*, UN Doc A/810, art 25(1).

<sup>104</sup> *UDHR*, UN Doc A/810, art 25(1).

<sup>105</sup> *UDHR*, UN Doc A/810, art 25(2).

people's right to an adequate standard of living, which in circumstances of particular need or marginalisation may include directly providing the means and resources for the enjoyment of this right.<sup>106</sup> Therefore although there is no direct reference to 'support', these articles place an obligation on the State to provide support services to individuals with particular impairments.

38. This right is also incorporated within Article 11 of the *International Covenant on Economic, Social and Cultural Rights (ICESCR)*. Article 11 provides for the recognition of the right of everyone to an adequate standard of living and places an obligation on States to 'take appropriate steps' towards realisation of this right.<sup>107</sup> While again no reference is here made to 'support', appropriate steps to achieve this right may include the provision of support to those who would not otherwise be able to achieve an adequate standard of living.

39. Article 28 of the CRPD provides for a right of persons with disabilities to an adequate standard of living and social protection. This reiterates the requirement to take 'appropriate steps', which includes measures to ensure access to various services and programs. The *Draft Protocol* contains Article 16, titled 'Right to Adequate Standard of Living and the Right to Social Protection'.<sup>108</sup> This further elucidates what 'appropriate and effective measures to facilitate full enjoyment by persons with disabilities of this right' may require. It can include providing access to mobility aids and carers, and 'facilitating provision of assisters, such as interpreters, guides, auxiliary and augmentative supporters and carers'.<sup>109</sup> This illustrates that the right to support as recognised in the CRPD has been embraced more broadly as a human right.

#### **D Right to Education**

40. Article 26 of the UDHR provides for the right of everyone to education, including free education in at least the elementary and fundamental stages.<sup>110</sup> This places an obligation on States to provide for at least some free education. The *Incheon Declaration* reaffirms

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<sup>106</sup> David Harris (ed), *International Human Rights Law* (Oxford University Press, 2<sup>nd</sup> ed, 2013) 236-7.

<sup>107</sup> *ICESCR*, 993 UNTS 3, art 11.

<sup>108</sup> Draft Protocol to African Charter art 16.

<sup>109</sup> Draft Protocol to African Charter art 16.

<sup>110</sup> *UDHR*, UN Doc A/810, art 26.

that education is a fundamental human right and one that is necessary for the enjoyment of other human rights.<sup>111</sup> The right is also recognised in Article 13 of the ICESCR which requires free primary education available to all.<sup>112</sup> Although a requirement of free education does not explicitly require that ‘support’ be provided, it does demonstrate that States have a positive obligation to provide for education to ensure that everyone is able to access it. The Committee on Economic, Social and Cultural Rights have stated that ‘it is clear that article 13 regards States as having principal responsibility for the direct provision of education in most circumstances’.<sup>113</sup> This illustrates the importance of equality of opportunity in accessing education. It also demonstrates that the State has an obligation to make education available and accessible to everyone, and to ensure this; which may require policy measures or positive obligations including measures of support.<sup>114</sup>

41. The CRPD goes further, explicitly requiring that to realise this right without discrimination and on the basis of equality of opportunity, States shall ensure that support is provided as needed.<sup>115</sup> However, while the explicit obligation to provide ‘support’ is not included within previous human rights instruments, the obligation to ensure equal access to such an essential right implies the requirement of support and assistance where it is necessary to ensure such equality of education for persons with disabilities.
42. Article 12 of the *Draft Protocol* extends on the right to education as expressed in prior human rights instruments.<sup>116</sup> In requiring that States ensure access of persons with disabilities to education on an equal basis with others Article 12 of the Draft Protocol also requires that States take ‘appropriate and effective measures to ensure that the goal of inclusive education for persons with disabilities is realised fully’. The Draft Protocol therefore requires that ‘[r]easonable accommodation of the individual’s requirements is provided, and that persons with disabilities receive the support required to facilitate their

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<sup>111</sup> World Economic Forum, *Incheon Declaration: Education 2030: Towards inclusive and equitable quality education and lifelong learning for all*, ED/WEF2015/MD/3 (22 May 2015) [5].

<sup>112</sup> ICESCR, 993 UNTS 3, art 13.

<sup>113</sup> Committee on Economic, Social and Cultural Rights, *General Comment 13*, E/C.12/1999/105 (8 December 1999) [48].

<sup>114</sup> Harris, above n 106, 290-1.

<sup>115</sup> CRPD, 999 UNTS, art 24.

<sup>116</sup> Draft Protocol to African Charter art 12.

effective education’ and that ‘[e]ffective individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion’.<sup>117</sup>

43. Acceptance of the requirement to provide support and assistance is illustrated by legislation requiring additional support for persons with disabilities. For example, in the Czech Republic, s 16(7) of the amended *Education Act 2004* provides that ‘[d]isabled children... shall be, during their education, entitled to the free use of special textbooks and special didactical and compensatory teaching aids provided by the school’. In Nauru, the *Education Act 2011* provides for ‘special educational needs’ requiring ‘tailored ... support and assistance’<sup>118</sup> and requires that ‘students with disabilities receive the support required, within the general education system, to facilitate their effective education’<sup>119</sup> and that ‘effective individualised support measures are provided to students with disabilities ... consistent with the goal of full inclusion’.<sup>120</sup> In Serbia, Article 77 of the *Law on the Fundamentals of the Education System 2009* states that ‘[a]n institution shall eliminate physical and communication obstacles and adopt individual education plan for child or pupil in need of additional educational and pedagogical support, due to ... developmental impairment, physical disability or for other reasons’.<sup>121</sup> Therefore, there is broad acceptance of the right to support in both human rights instruments and domestic legislation.

### **E Part V Conclusion**

44. This part has demonstrated that the notion of support is implicitly present in human rights instruments and then explicitly elaborated on in the CRPD and later documents modelled on the CRPD.

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<sup>117</sup> Draft Protocol to African Charter art 12(4).

<sup>118</sup> *Education Act 2011* s 4 (definition: special educational needs) (Nauru).

<sup>119</sup> *Education Act 2011* s 95(c) (Nauru).

<sup>120</sup> *Education Act 2011* s 95(d) (Nauru).

<sup>121</sup> United Nations Educational, Scientific and Cultural Organisation, *Implementing the Right to Education: A Compendium of practical examples Based on Eighth Consultation of Member States on the Implementation of the Convention and Recommendation against Discrimination (2011-2013)*, (2016) 31-32.

## VI HUMAN RIGHTS PRINCIPLES

### A Introduction

45. The obligation to provide support can be derived from human rights principles. Human dignity is one of the central binding norms for human rights.<sup>122</sup> The Preamble of the UDHR treats human dignity as fundamental and inalienable.<sup>123</sup> Respecting human dignity requires recognition of freedom and equality of all human beings. This entails recognising the inherent value of all persons, including those with disabilities.<sup>124</sup> Therefore, all persons are subjects of inalienable rights, or ends in themselves, and not merely objects or means to an end.<sup>125</sup> The inherent dignity of the person necessitates that he or she be the prime focus of all decisions regarding or affecting him or her.<sup>126</sup> In that sense it is the basis for other key human rights principles of individual autonomy; equality and non-discrimination; and participation and inclusion, discussed below.
46. Prior to the introduction of the CRPD, the *World Programme of Action* and the *United Nations Standard Rules* did not take the same human rights approach grounded in core human rights principles of non-discrimination, participation, inclusion and autonomy as is now taken under the CRPD.<sup>127</sup> These key principles function as goals of the CRPD.<sup>128</sup> The CRPD elaborates on the State obligations to achieve human rights for persons with disabilities.<sup>129</sup> Article 4 of the CRPD outlines the general obligations on States and requires States to undertake measures to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities, without discrimination based on disability.<sup>130</sup> Article 3 of the CRPD outlines the general human rights principles, including: non-discrimination, equal opportunity and participation,

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<sup>122</sup> Quinn and Degener, above n 26, 14.

<sup>123</sup> Heiner Bielefeldt, 'Philosophical and Historical Foundations of Human Rights' in Catarina Krause and Martin Scheinin (eds), *International Protection of Human Rights: A Textbook* (Abo Akademi University Institute for Human Rights, 2009) 3, 7.

<sup>124</sup> Quinn and Degener, above n 26, 14.

<sup>125</sup> Ibid.

<sup>126</sup> Ibid.

<sup>127</sup> Ibid 22.

<sup>128</sup> Committee on the Rights of Persons with Disabilities, *Decision: Communication No. 1/2010*, 9<sup>th</sup> sess, CRPD/C/9/d/1/2010 (21 June 2013) [3.2] ('*Nyusti, Takacs, & Fazekas v Hungary*').

<sup>129</sup> Quinn and Degener, above n 26, 23.

<sup>130</sup> Ibid.

which guide the interpretation and application of the CRPD.<sup>131</sup> These principles entrench human rights in the CRPD.<sup>132</sup>

47. This part will demonstrate that the universality of human rights principles provides an obligation on the States to promote full realisation of rights for all persons. The part below will demonstrate that the right to support can be justified on the basis of some of the fundamental principles of individual autonomy; equality and non-discrimination; and participation and inclusion.

### **B *Universality***

48. The international human rights framework sets out universal human rights. The Preamble to the UDHR states that human rights function as ‘a common standard of achievement for all peoples and all nations’. The universal nature of human rights requires the recognition that people are ‘born free and equal in dignity and rights’.<sup>133</sup> All people are equally entitled to human rights by virtue of their humanity and status as ‘bearers of human dignity’.<sup>134</sup> Therefore, all human rights should be able to be enjoyed by persons with disabilities on an equal basis with others. Paragraphs (b) and (c) of the Preamble to the CRPD reaffirm the universality of all human rights and the need for persons with disabilities to be guaranteed the full enjoyment of their human rights. The universality of human rights implies that everyone is entitled to human rights. Given this, and the recognition that disability results from a failure of States to remove barriers created by the interaction of impairment with the environment, there is a clear basis for a requirement that States take positive action to ensure that persons with disabilities are not denied equal enjoyment of their human rights. Additionally, the discussion about impairment, earlier in this paper, demonstrates that support may be necessary for persons with disabilities to enjoy human rights on an equal basis.

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<sup>131</sup> Quinn and Degener, above 26, 27.

<sup>132</sup> Ibid 28.

<sup>133</sup> *UDHR*, UN Doc A/810, art 1.

<sup>134</sup> Bielefeldt, above n 123, 7.

### C *Individual autonomy*

49. Autonomy encompasses the idea that a person must be free to make his or her own choices.<sup>135</sup> It is strongly linked with the idea of human dignity as the status of the individual as an ends in himself or herself requires recognition of his or her autonomy.<sup>136</sup> Andrew Power, Janet Lord and Alison DeFranco emphasise that while human rights treaties do not themselves generally contain the term ‘individual self-determination’ or ‘autonomy’, there is frequently recognition of these terms in human rights practice.<sup>137</sup> Autonomy is also recognised as a founding principle in human rights jurisprudence; for example, the European Court of Human Rights has repeatedly stated the importance of the principle of personal autonomy in understanding and interpreting the guarantees in the *European Convention of Human Rights*.<sup>138</sup> Quinn and Degener have also emphasised its status as a principle underlying human rights.<sup>139</sup> Its importance in the context of disability has been recognised,<sup>140</sup> and it is a principle enshrined in the CRPD.<sup>141</sup>
50. Individual autonomy requires that people freely determine their own lives.<sup>142</sup> They must be placed at the centre of all decisions affecting them.<sup>143</sup>
51. Traditionally, cognition and rationality were treated as indicia of the ability to exercise autonomy and this led to the denial of legal personhood to many persons with disabilities.<sup>144</sup> However, the CRPD recognises the ability of all human beings to express their will and preferences and make their own decisions with the appropriate support.<sup>145</sup> It therefore protects persons with disabilities from a denial of their personhood or autonomy.<sup>146</sup> It confirms that ‘persons with disabilities enjoy legal capacity on an equal

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<sup>135</sup> Power, Lord and DeFranco, above n 2, 31; General Comment No 1: Article 12, CRPD/C/GC/1, [14].

<sup>136</sup> Quinn and Degener, above n 26, 15.

<sup>137</sup> Power, Lord and DeFranco, above n 2, 31.

<sup>138</sup> Power, Lord and DeFranco, above n 2, 32; Quinn and Degener, above n 26, 74.

<sup>139</sup> Quinn and Degener, above n 26, 74.

<sup>140</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report No 124 (2014) 29 [1.37].

<sup>141</sup> CRPD, 999 UNTS, art 3(a).

<sup>142</sup> Nicole Hassoun, ‘Raz on the Right to Autonomy’ (2014) 22(1) *European Journal of Philosophy* 96, 97.

<sup>143</sup> Quinn and Degener, above n 26, 1.

<sup>144</sup> Eilionoir Flynn and Anna Arstein-Kerslake, ‘Legislating personhood: realising the right to support in exercising legal capacity’ (2014) 10(1) *International Journal of Law in Context* 81, 81-2.

<sup>145</sup> Ibid, 84; CRPD, 999 UNTS, art 12; General Comment No 1: Article 12, CRPD/C/GC/1.

<sup>146</sup> CRPD, 999 UNTS, art 12.

basis with others in all aspects of life'<sup>147</sup> and requires that measures relating to the exercise of legal capacity must respect the will and preferences of the person.<sup>148</sup> Article 12 of the CRPD prohibits discriminatory denial of the legal capacity of persons with disabilities and requires support be provided to enable the exercise of legal capacity and the expression of their will and preferences.<sup>149</sup> It requires that the individual autonomy of persons with disabilities always be respected.<sup>150</sup>

52. The right to support in the context of equal recognition before the law can also be justified on the basis of the principle of autonomy. Legal capacity is essential for meaningful participation in society.<sup>151</sup> Legal capacity requires legal agency, which involves the ability to act on one's rights and to have those rights recognised by the law.<sup>152</sup> Legal capacity is essential to the exercise of autonomy as it ensures the right to make one's own decisions.<sup>153</sup> The right to equal recognition as a person before the law is essential to the exercise of autonomy,<sup>154</sup> and to the exercise of other human rights.<sup>155</sup> The right to support for legal capacity is an essential component of respecting the principle of autonomy in relation to disabled persons.

53. Disability scholars' and activists' calls for independence and support have offered a challenge to traditional concepts of autonomy and independence. As Jenny Morris explains, independence for persons with disabilities does not necessarily mean self-sufficiency, but rather the right 'to adequate support which would give them choice and control in their lives'.<sup>156</sup> Autonomy can only be fully and effectively enjoyed with the support of others.<sup>157</sup> This further involves recognition that all humans are interdependent – at some times in our lives, we all require support, and most of us will also give

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<sup>147</sup> *CRPD*, 999 UNTS, art 12(2).

<sup>148</sup> *CRPD*, 999 UNTS, art 12(4).

<sup>149</sup> General Comment No 1: Article 12, *CRPD/C/GC/1*, [15]; *CRPD*, 999 UNTS, arts 12(2), 12(3).

<sup>150</sup> General Comment No 1: Article 12, *CRPD/C/GC/1*, [18].

<sup>151</sup> General Comment No 1: Article 12, *CRPD/C/GC/1*, [13].

<sup>152</sup> General Comment No 1: Article 12, *CRPD/C/GC/1*, [13].

<sup>153</sup> Quinn and Arstein-Kerslake, above n 61, 42.

<sup>154</sup> Quinn and Arstein-Kerslake, above n 61, 41.

<sup>155</sup> General Comment No 1: Article 12, *CRPD/C/GC/1*, [1].

<sup>156</sup> Jenny Morris, above n 72, 55.

<sup>157</sup> Quinn and Arstein-Kerslake, above n 61, 40.

support.<sup>158</sup> By recognising that the exercise of legal capacity of persons with disabilities sometimes necessitates support, the CRPD acknowledges that the enjoyment of substantial equality is only possible where both the rights to autonomy and to support are recognised.<sup>159</sup> Therefore it recognises that individuals can only be autonomous when support is provided.<sup>160</sup>

54. States are obliged to replace regimes involving substituted decision-making and replace these with supported decision-making ‘which respects the person’s autonomy, will and preferences’.<sup>161</sup> This is illustrated by the requirement that States are obligated to provide for safeguards in relation to the exercise of legal capacity by persons with disability that respect their ‘rights, will and preferences’ and the CRPD’s strong commitment to providing support in this context.<sup>162</sup>

55. The Committee on the Rights of Persons with Disabilities has stated that Article 12 does not set out additional rights for persons with disabilities but instead describes specific elements that States are required to take into account to ensure the right of persons with disabilities to substantive equality before the law, on an equal basis.<sup>163</sup>

#### **D Non-discrimination and Equality**

56. Equality and non-discrimination are related principles that underlie all other human rights.<sup>164</sup> They will be used interchangeably in this paper. Equality is a fundamental principle of human rights.<sup>165</sup> The right to equality and non-discrimination is included in the core human rights instruments,<sup>166</sup> including the CRPD, the ICCPR, the UDHR and the

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<sup>158</sup> Ibid; Fiona Williams ‘In and beyond new labour: Towards a new political ethics of care’ (2001) 21(4), *Critical Social Policy*, 467-93, 486-7.

<sup>159</sup> Tina Minkowitz ‘The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from non-consensual psychiatric interventions’ (2007) 34(2) *Syracuse Journal of International Law and Commerce* 405, 408.

<sup>160</sup> Ibid, 409.

<sup>161</sup> Ibid [26].

<sup>162</sup> CRPD, 999 UNTS, art 12(4).

<sup>163</sup> General Comment No 1: Article 12, CRPD/C/GC/1, [1].

<sup>164</sup> Harris, above n 106, 193.

<sup>165</sup> Degener, above n 23, 15; Human Rights Committee, *General Comment No 18 Non-Discrimination*, 37<sup>th</sup> sess, UN Doc HRI/GEN/1/Rev 1 (10 November 1989) [1] (‘General Comment No 18 Non-Discrimination’).

<sup>166</sup> ICCPR, 999 UNTS 171, art 26; ICESCR, 993 UNTS 3, arts 2(2), 3; UDHR, UN Doc A/810, arts 1, 2(1), 7; Harris, above n 106, 190.

ICESCR.<sup>167</sup> The *Vienna Declaration and Programme of Action*, adopted by the World Conference on Human Rights in 1993, describes it as ‘a fundamental rule of international human rights law’.<sup>168</sup> The *Vienna Declaration and Programme of Action* analyses and clarifies the international human rights system.<sup>169</sup>

57. A failure to provide for reasonable accommodation can be a form of discrimination.<sup>170</sup> The equality and non-discrimination principle contained within the CRPD also incorporates a duty to provide for accessibility, and therefore recognises that meeting the obligation of non-discrimination has both a group and an individual component.<sup>171</sup>
58. The Committee on Economic and Social and Cultural Rights has recognised that non-discrimination and equality encompass not just formal, but also substantive equality.<sup>172</sup> Equality of opportunity can be substantive or formal equality.<sup>173</sup> Degener and Andrea Broderick both posit a third model of equality; transformative equality.<sup>174</sup> Formal equality seeks to address direct discrimination by treating people in similar circumstances similarly and treating differently situated people differently.<sup>175</sup> Substantive equality on the other hand takes into account power relations and seeks to address structural and indirect forms of discrimination.<sup>176</sup> Transformative equality seeks not just the removal of barriers to inclusion, but also involves positive measures towards addressing hierarchical power relations.<sup>177</sup> It is now well established in human rights law that States have an obligation to take proactive steps to eliminate structural disadvantages and promote social inclusion.<sup>178</sup> The Human Rights Committee have highlighted that the ICCPR expressly requires positive measures to be taken to guarantee equality of rights and non-

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<sup>167</sup> CRPD, 999 UNTS, art 5.

<sup>168</sup> Harris, above n 106, 190; UN General Assembly, *Vienna Declaration and Programme of Action*, GA Res 48/121, A/CONF 157/23 (12 July 1993) 1 (‘Vienna Declaration and Programme of Action’).

<sup>169</sup> Vienna Declaration and Programme of Action, 1.

<sup>170</sup> CRPD, 999 UNTS, art 2.

<sup>171</sup> Degener, above n 23, 16.

<sup>172</sup> Committee on Economic, Social and Cultural Rights, *General Comment No. 22 (2016) on the Right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)*, E/C.12/GC/22 (4 March 2016) [24].

<sup>173</sup> Harris, above n 106, 193.

<sup>174</sup> Degener, above n 23, 18; Andrea Broderick, ‘The Long and Winding Road to Equality and Inclusion for Persons with Disabilities’ (2015) 15(1-2) *International Journal of Discrimination and the Law* 62, 63.

<sup>175</sup> Degener, above n 23, 17.

<sup>176</sup> Ibid.

<sup>177</sup> Ibid.

<sup>178</sup> Harris, above n 106, 205.

discrimination in some instances.<sup>179</sup> Therefore a substantive or transformative approach is favoured over a formal equality approach.

59. It is not sufficient for States to merely promote formal equality because treating people that are different in the same manner in many circumstances does not achieve equality but may perpetuate the difference.<sup>180</sup> To achieve substantive or transformative equality of opportunity States may be required to take affirmative action or implement positive obligations.<sup>181</sup> The Human Rights Committee have recognised that the principle of equality requires positive action to eliminate or diminish conditions creating or reinforcing discrimination in certain circumstances.<sup>182</sup> Therefore, an approach which allows for positive obligations to redress indirect discrimination, rather than formal equality, is recognised as the most appropriate approach under the human rights perspective in achieving equality.<sup>183</sup> According to Gerard Quinn and Degener, ensuring equality of opportunity for persons with disabilities requires government intervention to eliminate various barriers that hinder equal standing in society, to promote participation and to remove discrimination.<sup>184</sup> Social structures should be designed to recognise that every human being has something to contribute to humanity.<sup>185</sup> Through the provision of support and assistance, governments are able to empower persons with disabilities and achieve greater equality.<sup>186</sup> Support services should be tailored to individuals which allow persons with disabilities to have equal opportunities in all areas of life.

### **E Participation and Inclusion**

60. Participation and inclusion are essential principles of human rights because of their importance as both ends and means of achieving human rights, as we will demonstrate. They refer to closely linked concepts that are often used interchangeably; inclusion can be achieved by allowing people to participate, while participation requires people to be

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<sup>179</sup> General Comment No 18 Non-Discrimination, UN Doc HRI/GEN/1/Rev, [5].

<sup>180</sup> Smith, above n 36.

<sup>181</sup> Ibid.

<sup>182</sup> General Comment No 18 Non-Discrimination, UN Doc HRI/GEN/1/Rev, [10].

<sup>183</sup> Quinn and Degener, above n 26, 17-18; European Commission, *Reasonable Accommodation beyond Disability in Europe?* (2013) 38; Nicholas Bamforth, Maleiha Malik and Colm O'Conneide, *Discrimination Law: Theory and Context* (Sweet & Maxwell, 2008) 1072.

<sup>184</sup> Quinn and Degener, above n 26, 17.

<sup>185</sup> Ibid 17-18.

<sup>186</sup> Power, Lord and DeFranco, above n 2, 35-40.

included. One way to distinguish between the concepts is that participation can be used to refer to an individual's ability to exercise agency, while inclusion focuses more on the need for society to adapt to and accommodate difference.

61. Participation is a core human rights principle and a basic condition of democratic societies.<sup>187</sup> While central human rights instruments do not always refer to the right to participation, they incorporate the principle of participation. For example, the UDHR sets out that every person has a right to take part in the government and right to equal access to public services.<sup>188</sup> The ICCPR reaffirms the commitment of human rights to participation through the rights to equal participation in public affairs, the right to vote and be elected, and the right to have equal access to public services.<sup>189</sup> It is also a principle at the heart of the CRPD.<sup>190</sup> The CRPD makes express or implicit reference to participation in a number of its provisions.<sup>191</sup> Participation is therefore an ends to be strived for in a society that respects human rights.
62. Participation and inclusion are means because of their intrinsic link to autonomy, equality and human dignity - if people are excluded from the process of participating in decisions affecting them, then this will impinge on their autonomy. Recognising people's right to participate in a decision is essential to recognising their equal dignity.
63. Human rights are intended to achieve the equal participation and inclusion of all people,<sup>192</sup> as is illustrated by, *inter alia*, the inclusion of '[f]ull and effective participation and inclusion in society'<sup>193</sup> as a principle of the CRPD. Civil and political rights enable people to participate and be included within politics and society, and in doing so also promote autonomy.<sup>194</sup> Economic, social and cultural rights seek to empower people to

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<sup>187</sup> Catalina Devandas-Aguilar, *Report of the Special Rapporteur on the rights of persons with disabilities*, 71<sup>st</sup> sess, UN Doc A/71/314 (9 August 2016) 4.

<sup>188</sup> *UDHR*, UN Doc A/810, art 21.

<sup>189</sup> *ICCPR*, 999 UNTS 171, art 25.

<sup>190</sup> *CRPD*, 999 UNTS, arts 1, 3, 29.

<sup>191</sup> *CRPD*, 999 UNTS, 7, 9, 19, 21, 24, 26, 30.

<sup>192</sup> Power, Lord and DeFranco, above n 2, 18.

<sup>193</sup> *CRPD*, 999 UNTS, art 3.

<sup>194</sup> Power, Lord and DeFranco, above n 2, 21.

participate in the labour market, the community and to be included within society.<sup>195</sup> This therefore also promotes their ability to be a self-determining autonomous agent.

64. The right of participation established in the CRPD extends to the right of persons with disabilities to participate on an equal basis with others in decision-making processes affecting their interests.<sup>196</sup> This requires that persons with disabilities not only be given the opportunity to express their views, but also to be heard and to have due weight accorded to their views, as illustrated by Article 12.<sup>197</sup> This is particularly important in regards to the concept of personalisation and the way in which support is implemented.<sup>198</sup> As discussed above, personalisation involves the shift from provision of paternalistic services towards provision of supports which promote autonomy, individual choice and the recognition of legal capacity.<sup>199</sup>

65. The obligation to provide for the participation of individuals is a basis for a further right to support. Full and effective participation of persons with disabilities requires the provision of support. For instance, the CRPD provides in Article 19 that the equal right of all persons with disabilities to live independently in the community, with equal choices to others, requires the full inclusion and participation of such persons. It requires that States provide ‘access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.’<sup>200</sup> Support is also necessary for persons with disabilities to enjoy their right to equal recognition before the law.<sup>201</sup> For instance, as discussed above, the right to equal recognition before the law is recognised in Article 26 of the ICCPR, but whereas Article 26 focuses on freedom from discrimination, Article 12 of the CRPD focuses on equal standing before the law, by recognising that persons with disabilities enjoy legal capacity on an equal basis with others and requiring States to provide support to ensure persons with disabilities are able to exercise their legal capacity.

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<sup>195</sup> Ibid 21-22.

<sup>196</sup> Ibid 33.

<sup>197</sup> Ibid.

<sup>198</sup> Ibid 33-34.

<sup>199</sup> Ibid 30.

<sup>200</sup> *CRPD*, 999 UNTS, art 19.

<sup>201</sup> *CRPD*, 999 UNTS, art 12.

## **F Part VI Conclusion**

66. Therefore, these fundamental principles of human rights law provide an additional basis for the State obligation to provide support to persons with disabilities.

## **VII CONCLUSION**

67. The obligation to provide support can be distinguished from the obligation to provide accessibility and reasonable accommodation measures. The importance of support as compared with reasonable accommodation is that the obligation to provide support is not limited by a qualification that the measure only imposes a 'reasonable' burden; it therefore is a more significant obligation. The obligation on the States to provide support can be found in human rights principles and in specific widely recognised human rights. Additionally, the CRPD elaborates on how these human rights should be applied in the context of disability and explicitly provides for a cross-cutting obligation on States to provide support.

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