

‘NOTHING ABOUT US WITHOUT US’: DISABLED PEOPLE DETERMINING THEIR HUMAN RIGHTS THROUGH THE UNCRPD

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The human rights and fundamental freedoms of disabled persons are set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This paper firstly focuses on the importance of the involvement of disabled people at all levels of decision-making. The second part of the paper identifies those aspects of the UNCRPD that reflect the direct involvement of disabled people. Finally, it considers how human rights bodies can best build on this specific aspect of the UNCRPD in order to realize the potential of the Convention as a determining factor in affirming disabled people rights in an effective and meaningful manner.

1. Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)¹ was adopted in 2006, opened for signatures in 2007 and came into force in 2008. The UNCRPD has to date been ratified by 173 countries. This Convention covers a wide range of areas and aspects of life that impinge on the rights of disabled persons, including the right to life through to the right to education, employment, health and rehabilitation, an adequate standard of living and social protection, family life, independent living, and participation in cultural and in political and

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¹ United Nations (2006) United Nations Convention on the Rights of Persons with Disabilities. Retrieved from: <http://www.un.org/disabilities/default.asp?id=150>

public life. These are areas in which disabled persons have a right to equal opportunities and non-discrimination on the ground of disability. Crucially, the UNCRPD does not only determine the rights that disabled persons have in these areas. It also puts a lot of weight on the importance of disabled people's autonomy, choice and control over their own lives, and participation in decision-making processes that affect them. It is their perspectives which matter most and it is they who must ultimately decide whether the implementation of the UNCRPD is translating into tangible positive changes in their lives.

In this paper we argue that any human rights body involved in the implementation of the UNCRPD needs to maintain close links with disabled people and to actively involve them and give primary importance to their perspective in its own work. We first focus on one of the many vitally important outcomes of the disabled people's movement: the insistence on the involvement of disabled people at all levels of decision making, embodied in the slogan 'Nothing about us without us'. We also consider how this slogan informed the process by which the UNCRPD was formulated. Next, we identify those aspects of the UNCRPD that reflect this characteristic of the disabled people's movement, analyzing the relevant parts of the Preamble as well as specific articles and sub-articles. Finally, we consider how human rights bodies can best build on this specific aspect of the UNCRPD in order to realize the potential of the Convention as a determining factor in affirming disabled people rights in an effective and meaningful manner, which entails practical arrangements that ensure that impairment-related requirements are truly catered for.

2. 'Nothing About Us Without Us': The journey from powerlessness to control

Over the past five or six decades, disabled people and their allies have organized themselves into a political and social force to challenge the oppression and exclusion experienced by disabled people². The disability rights movement is very often viewed as the last

² J. Campbell, & M. Oliver (1996) *Disability Politics: Understanding Our Past Changing Our Future*. London: Routledge.
J. Charlton (1998) *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.

civil rights movement in a long series of liberation movements, namely the workers' movement, the Black-American civil rights movement and the women's movement. These movements all engaged in the long historical struggle for human and civil rights³. According to Driedger even in places where some groups of disabled people are considered to have organized themselves relatively early, such as Sweden, other groups mentioned above had already organized themselves before them. Ed Roberts, one of the leading pioneers of the international Disability Rights Movement claims that a number of lessons were learnt from previous movements particularly from the Black-Americans civil rights movement: "If we have learned one thing from the civil rights movement in the U.S., it's that when others speak for you, you lose"⁴. Furthermore, it is in this sense that slogans such as "Our bodies, ourselves" and "Power to the people" are often recognized as precedents to the slogan used by disabled people, "Nothing about us without us"⁵.

Disability has traditionally been widely viewed as a failing on the part of the individual, as a personal tragedy and as a burden on the rest of society. In Western industrialized societies, for a long time, disability has mostly been described in terms of medical or biological deficits, with a focus on abnormality, disorders and conditions and how these were the cause of functional limitation and 'disability'⁶. According to French and Swain⁷, these views of disability are based on the general assumption that the difficulties experienced by disabled people are a direct result of their physical, sensory or intellectual impairment. Such descriptions of disability only lead to the interpretation of disabled people as individuals who are helpless, dependent, and incapable of making their own decisions⁸. In addition, the opinions of disabled people on the subject of

³ D. Driedger (1989) *The Last Civil Rights Movement: Disabled People's International*. London: C. Hurst and Co. Limited.

⁴ Ibid.

⁵ J. Charlton (1998) *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley: University of California Press.
J. Vaughn Switzer (2003). *Disabled Rights: American Disability Policy and the Fight for Equality*. Washington, D.C.: Georgetown University Press.

⁶ C. Barnes, Colin, & G. Mercer (2010) *Exploring Disability* (2nd ed.). Cambridge: Polity Press.

⁷ S. French, & J. Swain (2008) *Understanding Disability: A Guide for Health Professionals*. Edinburgh: Elsevier.

⁸ A. M. Duane (2014) "Volunteering as Tribute: Disability, Globalization and The Hunger Games," in M. Gill & C. J. Schlund-Vials, eds. *Disability, Human Rights and the Limits of Humanitarianism*. Surrey: Ashgate Publishing Limited.

A. Shearer (1981) *Disability – Whose Handicap?*. Blackwell: Basil.

disability are often not awarded with the same credibility and validity as the opinions of ‘experts’, particularly those of medical and health and social care professionals⁹. As a result of these views and assumptions, disabled people are often considered to be one of the most oppressed groups in society with non-disabled people and organisations, including professionals and charities, as being the cause of this oppression¹⁰.

As a result of the oppression experienced by disabled people in all aspects of their lives, a disability rights movement was formed. The movement stemmed from disabled people’s realization that their needs were not being met and that they did not have access to the same rights as the rest of society. Disabled people also realized that societies were built without their input and active participation¹¹. In addition, disabled people came to realize that civil rights, rather than charity or pity, is the answer to solving their problems. It was in the 1980s that disabled people all over the world took up the fight for equality and participation on an equal basis with others. A result of this realization was one of the biggest gatherings, of over four hundred disabled people, from fifty-three countries, in Singapore, in 1981 to form what is now known as Disabled People’s International (DPI)¹². According to Driedger¹³, disabled people gathered for one of the largest meetings with the aim “to proclaim they would no longer be silent” (p. 48). The formation of DPI came after a landmark event, the walking out of disabled people from the Rehabilitation International (RI) conference in Winnipeg, Canada in 1980. This

⁹ S. Brisenden (1986) “Independent Living and the Medical Model of Disability,” in T. Shakespeare, ed. *The Disability Studies Reader*. London: Continuum.

L. Swartz (2013) “Between Faith and Doubt: Training Members of Disabled People’s Organisations in Southern Africa in Basic Research Skills,” in J. Claassens, L. Swartz, & L. Hansen, eds. *Searching for Dignity: Conversations on Human Dignity, Theology and Disability*. California: SUN MeDIA.

¹⁰ T. Shakespeare (2013) “The Social Model of Disability,” in L. J. Davis, ed. *The Disability Studies Reader*. New York: Routledge.

¹¹ D. Driedger (1989) *The Last Civil Rights Movement: Disabled People’s International*. London: C. Hurst and Co. Limited.

¹² Disabled People’s International (DPI) (1982) *Disabled Peoples’ International. Proceedings of the First World Congress, Singapore*. Singapore: DPI.

¹³ D. Driedger (1989) *The Last Civil Rights Movement: Disabled People’s International*. London: C. Hurst and Co. Limited.

was a historical move which saw disabled people standing up to and challenging the dominance of health professionals who till then tended to control the disability agenda¹⁴.

DPI's mandate is to be the direct voice of disabled people across the world. It is considered to be the first international organization which successfully brings together people of different impairments with the aim of creating a united voice. It firmly believes in and was set up on the premise that disabled people are to be included in all aspects of society and to participate with the same rights as everyone else. DPI is a holder of the belief that there is strength in numbers and that speaking unitedly disabled people's voices can have a greater impact than when speaking on their own¹⁵. DPI is an activist-oriented organisation and has since lobbied both governments and the United Nations and has more recently been largely instrumental in the drafting of the UNCRPD. However, the establishment of DPI has also led to other previous important events and initiatives which have certainly paved the way for the development of the UNCRPD, namely: the declaration by the UN of 1981 as the International Year of the Disabled Persons (IYPD); the World Programme of Action Concerning Disabled Persons; the proclamation by the UN of the Decade of Disabled Persons (1982-1992) which resulted in the drawing up of the Standard Rules on Equalisation of Opportunities for People with Disabilities; and the creation of a large number of disabled persons-led organisations¹⁶.

3. The Birth of the Social Model

One of the most significant outcomes of the disability rights movement is the social model of disability. The model is known to have been primarily developed in Britain by the Union of the Physically Impaired Against Segregation (UPIAS) who in the 1970s published the

¹⁴ G. Mji, S. Gcaza, N. Melling-Williams, & M. MacLachlan (2009) "Networking in Disability for Development: Introducing the African Network for Evidence-to-Action on Disability (AfriNEAD)," in M. MacLachlan & L. Swartz, eds. *Disability and International Development: Toward Inclusive Global Health*. London: Springer.

¹⁵ D. Driedger (1989) *The Last Civil Rights Movement: Disabled People's International*. London: C. Hurst and Co. Limited.

¹⁶ C. Howell, S. Chalklen, & T. Alberts (2006) "A History of Disability Rights in South Africa," in B. Watermeyer, L. Swartz, T. Lorenzo, & M. Priestley, eds. *Disability and Social Change – A South African Agenda*. Cape Town: HSRC.

paper titled ‘Fundamental Principles of Disability’¹⁷. The social model of disability was later also adopted by Disabled People’s International (DPI) during the World Congress held in Singapore in 1981¹⁸. The model has been critically important for the lives of disabled people and has been extremely influential both in Britain and internationally¹⁹. The social model of disability makes a very clear distinction between the definitions of impairment and disability. According to the social model of disability, impairment is taken to mean ‘the functional limitation within the individual caused by physical, mental or sensory impairment’²⁰, whilst disability is taken to mean ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers’²¹. The development of the social model of disability shows the first signs of disabled people taking control of their own lives by putting forward a model of disability which is contrary to the medical model. It is a model which places responsibility on society, and not on the disabled individual, to remove the material obstacles and cultural barriers encountered by disabled people which prevent them from exercising their rights and being fully included in society²². Barnes and Mercer²³ assert that the social model of disability creates a break in the traditional causal link between impairment and disability. More importantly, the social model of disability has acted as a spur for political and social change and has inspired many new laws and policies, including the UNCRPD²⁴.

Following more than two decades in the 1980s and 1990s of networking and relentless work by disabled people, and with the development of the social model of disability and the work by the disability rights movement, disabled people were able to tackle the years of

¹⁷ M. Oliver (1996) *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan.

¹⁸ C. Barnes, & G. Mercer (2010) *Exploring Disability* (2nd ed.). Cambridge: Polity Press.

¹⁹ R. Traustadottir (2009) “Disability Studies, The Social Model and Legal Developments,” in O. M. Arnardottir & G. Quinn, eds. *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*. Leiden: Martinus Nijhoff Publishers.

²⁰ Disabled People’s International (DPI) (1982) *Disabled Peoples’ International. Proceedings of the First World Congress, Singapore*. Singapore: DPI.

²¹ Ibid.

²² A. Kanter (2013) “The Relationship Between Disability Studies and Law,” in A. S. Kanter & B. A. Ferri, eds. *Rights Educational Wrongs: Disability Studies in Education and Law*. New York: Syracuse University Press.

²³ C. Barnes & G. Mercer (2010) *Exploring Disability* (2nd ed.). Cambridge: Polity Press.

²⁴ J. Harris, & A. Roulstone (2011) *Disability, Policy and Professional Practice*. London: Sage Publications Limited.

discrimination and oppression they have experienced through international legislation. The fruit of this work is the development of the United Nations Convention on the Rights of Persons with Disabilities, which as of 2008 entered into international law²⁵. The origin of the UNCRPD saw Mexico, in December 2001, propose in the UN's General Assembly the establishment of an Ad Hoc Committee which would consider proposals for an international convention aimed at promoting and protecting the rights of disabled people. Two years later, in August 2003, a working group was set up whose task it was to draft a text. Three years later, in December 2006, the Ad Hoc Committee adopted the final draft of the Convention and the Optional Protocol (OP), with the UNCRPD and OP opening for signatures in March 2007²⁶. Signing of the UNCRPD means that State Parties will refrain, in good faith, from acts that would defeat the objective and purpose of the Convention. Ratification means that State Parties are bound by international law to uphold and implement the 50 article of the UNCRPD²⁷. According to Kanter²⁸, "ratifications represent a new worldwide recognition of the rights of persons with disabilities that did not exist prior to the UNCRPD". The UNCRPD aims to remove long-standing barriers and obstacles between non-disabled people and disabled people. In addition, the implementation of the UNCRPD will result in the formation of domestic laws which would not only offer equal opportunities to disabled people but also to other marginalized groups²⁹.

One of the most significant aspects of the UNCRPD is that for the first time the people who were the target group of the Convention, that is disabled people, were directly involved in its drafting. Under the slogan 'Nothing about us without us', disabled people through their respective disabled people's organisations, participated actively both in the drafting and in the

²⁵ C. Howell, S. Chalklen, & T. Alberts (2006) "A History of Disability Rights in South Africa," in B. Watermeyer, L. Swartz, T. Lorenzo, & M. Priestley, eds. *Disability and Social Change – A South African Agenda*. Cape Town: HSRC.

²⁶ United Nations (n.d.) *Timeline of Events*. Retrieved from: <http://www.un.org/disabilities/default.asp?id=153>

²⁷ C. Howell, S. Chalklen, & T. Alberts (2006) "A History of Disability Rights in South Africa," in B. Watermeyer, L. Swartz, T. Lorenzo, & M. Priestley, eds. *Disability and Social Change – A South African Agenda*. Cape Town: HSRC.

²⁸ A. Kanter (2013) "The Relationship Between Disability Studies and Law," in A. S. Kanter & B. A. Ferri, eds. *Rights Educational Wrongs: Disability Studies in Education and Law*. New York: Syracuse University Press.

²⁹ Ibid.

negotiations on the text of the UNCRPD. According to de Beco and Hoefmans³⁰, the adoption of this particular slogan during the negotiations of the UNCRPD does not only symbolize the participation and influence of disabled people at all the stages of drafting of the UNUNCRPD, including in the Ad Hoc Committee, but also represents one of the most fundamental principles incorporated in the Convention, that is, disabled people's participation in decision making. In addition, the adoption of this slogan also symbolizes another principle which disabled people had been fighting for since their walking out of the Rehabilitation International conference in 1980 and the subsequent formation of DPI, that of control over the disability agenda and over their own lives. The slogan 'Nothing about without us', makes very explicit the fear held by disabled people that unless they are involved in the decision-making processes their needs will never be truly met³¹.

The direct involvement of disabled people did not lie solely at the drafting stage but a number of articles of the UNCRPD also make reference to the obligation of State Parties to involve civil society and disabled people's organizations (DPOs) in particular, in the implementation of the UNCRPD. In fact, influenced by the slogan 'Nothing about us, without us', the UNCRPD makes a particular emphasis on the involvement of disabled people's organizations (DPOs)³². Unlike any other disability non-governmental organization, DPOs are organisations which are led *by* disabled people and are thus distinct from those organizations which are *for* disabled people and run by mainly non-disabled people. In addition, as a rule, DPOs aim to represent and support the needs that their disabled members themselves would have

³⁰ G. de Beco, & A. Hoefmans (2013) "National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities," in G. De Beco, ed. Article 33 of the UN Convention on the Rights of Persons with Disabilities. Leiden: Martinus Nijhoff Publishers.

³¹ Disability-Uganda Webmasters (2012, January 22) *Disability Rights in Uganda – Research blog* [Blogpost]. Retrieved from <http://disability-uganda.blogspot.com.mt/2012/01/nothing-about-us-without-us.html>

³² G. de Beco, & A. Hoefmans (2013) "National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities," in G. De Beco, ed. Article 33 of the UN Convention on the Rights of Persons with Disabilities. Leiden: Martinus Nijhoff Publishers.

identified and defined³³. ‘DPOs are to disability rights what NGOs are to human rights in general’³⁴.

Furthermore, a particular issue which disabled people have been very vocal about since the formation of the disability rights movement and which is also enshrined in the UNCRPD is the definition of independence as understood by disabled people. The predominant meaning of independence by the general society, including professionals, is the ability to do things for oneself without anyone’s help. However, this meaning of independence has been greatly challenged by disabled people. According to disabled people, independence is viewed in terms of ‘self-determination, control and managing and organizing any assistance’ that may be required³⁵. Ryan and Holman³⁶ define independence as understood by disabled people as, ‘not necessarily...what you can do for yourself, but rather what others can do for you, in ways that you want it done’. In the broadest sense, being independent does not only imply that disabled people have the right to make ‘free and conscious choices’ concerning their own lives, but it also means having the right to take an active part in society³⁷. Indeed, the concept of independence is particularly enshrined in Article 19 of the UNCRPD whereby it is underlined that State Parties are to promote the empowerment of disabled people and to provide services which allow disabled people to exercise their right of independence³⁸.

In the UNCRPD, it is not only Article 19 that asserts the right of disabled people to direct participation in decision-making processes that affect them. We therefore now turn our attention

³³ R. Mallett, & K. Runswick-Cole (2014) *Approaching Disability: Critical Issues Inand Perspectives*. London: Routledge.

³⁴ G. de Beco, & A. Hoefmans (2013) “National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities,” in G. De Beco, ed. *Article 33 of the UN Convention on the Rights of Persons with Disabilities*. Leiden: Martinus Nijhoff Publishers.

³⁵ S. French, & J. Swain (2012) *Working with Disabled People in Policy and Practice: A Social Model*. Hampshire: Palgrave Macmillan.

³⁶ T. Ryan, & A. Holman (1998) *Able and Willing: Supporting People with Learning Difficulties to Use Direct Payments*. London: Values into Action.

³⁷ R. Forastiero (2014) “The Charter of Fundamental Rights and the Protection of Vulnerable Groups: Children, Elderly and Persons with Disabilities,” in G. Palmisano, ed. *Making the Charter of Fundamental Rights a Living Instrument*. Leiden: Brill Nijhoff.

³⁸ *Ibid.*

to the text of the Convention, highlighting how it promotes disabled people's autonomy and reinforces the demands encapsulated in the slogan 'Nothing about us without us'.

4. Disabled People's Right to Participation in Decision-Making

As a human rights instrument, the UNCRPD is based, among other things, on the Universal Declaration of Human Rights and the International Covenants on Human Rights, which are mentioned in the Preamble paragraph (b). Significantly, these treaties link human rights clearly with fundamental freedoms which are indivisible, interdependent and interrelated, and which belong to all disabled people (Preamble paragraph (c)). The promotion and protection of these rights and freedoms for disabled people is stated as the General Purpose of the Convention (Article 1).

The safeguarding of disabled people's rights is therefore not simply about ensuring that they have access to education, employment, community-life, information, communication, and goods, services and facilities. It is also about ensuring that this access is provided in a way that respects disabled people's right to choose and make decisions about their own lives. The Preamble of the UNCRPD states this clearly:

Recognizing the importance for persons with disabilities of their *individual autonomy and independence, including the freedom to make their own choices* (UNCRPD Preamble (n) our emphasis)

The Preamble also refers to the diversity of disabled people (paragraph j). This is directly related to a respect for disabled people's identity which is asserted in Article 30 (Participation in cultural life, recreation, leisure and sport).

Given the diversity of disabled people, it follows that for their human rights and fundamental freedoms to be respected, their individual needs have to be taken into account. And it is disabled people themselves, with support where necessary, who should determine what their own needs are. This emerges clearly from the first of the General Principles of the UNCRPD (Article 3):

- (a) Respect for inherent dignity, *individual autonomy including the freedom to make one's own choices, and independence of persons* (our emphasis)

This respect is in turn entrenched in the UNCRPD in Article 12 (Equal recognition before the law), which asserts that *all* disabled people have legal capacity and *all* have the right to be recognized as persons before the law. As the Committee for the Rights of Persons with Disabilities (REF) points out, legal and mental capacity should not be conflated. Therefore, the response to limitations in mental capacity should not be the removal of their legal capacity through substitute decision-making legislation, but the provision of support mechanisms and the enactment of supported decision-making legislation.

The exercise of legal capacity, with or without support, by disabled people takes place in everyday decisions as well as in potentially life-changing ones. The UNCRPD recognizes disabled people's rights to choose in specific areas. Article 19 (Living independently and being included in the community) is not simply about disabled people being physically in the community with non-disabled people and engaging in the same activities as them. It is also about the disabled person's right to choose what to do in the community, where to live and with whom. Even when it comes to the facilitation of personal mobility, Article 20 (Personal mobility) stipulates that this needs to happen 'in the manner and the time of their [disabled persons'] choice'.

Furthermore, the UNCRPD asserts disabled people's right to 'respect for his or her physical and mental integrity' (Article 17 Protecting the integrity of the person), their right not to

be deprived of their liberty on the basis of their disability (Article 14 Liberty and security of the person) and the right to freedom of expression and opinion (Article 21 Freedom of expression and opinion, and access to information). Tied to the latter is the importance of access to information and the respect of different forms of communication.

The UNCRPD does not stop at asserting the right of disabled people to take decisions about their own lives, and the provision of opportunities and support for them to do so. It also places responsibilities on States Parties to involve disabled people in decision-making processes at a higher level too. There are three instances where this happens.

In the Preamble we find:

Considering that persons with disabilities should have the opportunity *to be actively involved in decision-making processes* about policies and programmes, including those directly concerning them, (UNCRPD Preamble (o) our emphasis)

In Article 4 (General Obligations), States Parties are obliged to ‘closely consult and actively involve persons with disabilities’ in decisions related to the development and implementation of policies and legislation related to the UNCRPD itself (Article 4.3). Given that the UNCRPD covers all aspects of life, this effectively means that, once a country has ratified the UNCRPD, its government has to consult disabled people, including disabled children. This can be done through disabled people’s organisations (DPOs). As seen earlier, DPOs have a crucial role to play within the disability movement which is distinct from that of non-governmental organisations (NGOs) which are run by non-disabled people. While DPOs may share aims, objectives and working methods with other NGOs, the fact that they are controlled by disabled people themselves make them more representative.

The obligation for States Parties to actively involve disabled people and their representative organisations is also found in Article 33 (National implementation and monitoring). Like most UN Conventions, this Article establishes a focal point for the UNCRPD in Subarticle 1. However, unlike any other UN treaty to date, it also establishes an independent mechanism that is entrusted with the protection, promotion and monitoring of the implementation of the UNCRPD by States Parties in Subarticle 2. Additionally, both focal points and independent mechanisms must involve disabled people in their work. This requirement is specified in Article 33.3:

Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

In the next section, we focus on some examples of how the requirements of these two sub-articles have been implemented in the EU.

5. Implementation of Article 33 in 3 EU Member States: Italy, United Kingdom and Spain

The European Union (EU) is the only “regional integration organization” which has signed and ratified the Convention. In addition, the Convention is the first Human Rights Treaty to which the EU is a party. To date, all EU Member States have signed the Convention. However, Finland, Ireland and the Netherlands have not yet ratified the Convention. Twenty-three EU Member States have also signed the Optional Protocol, with 21 EU Member States having also ratified it³⁹.

Article 33.2 makes a direct reference to ‘the principles relating to the status and functioning of national institutions for protection and promotion of human rights’, known as the

³⁹ Fundamental Rights Agency (FRA) (2015) *Implementing the United Nations Convention on the Rights of Persons with Disabilities (UNUNCRPD): An Overview of Legal Reforms in EU Member States*. Vienna: European Union Agency for Fundamental Rights.

Paris Principles⁴⁰. However, while these principles offered detailed guidance for national human rights institutions to maintain their autonomy, their implementation with regard to the requirements of Articles 33.2 and 33.3 is proving to be no straightforward matter. Even State Parties to the UNCPRD are still in the process of examining ways how to implement them. Concrete guidelines and examples are still lacking due to the unprecedented and innovative nature of the provision presented in this article⁴¹. For the purpose of this paper we are going to look at how Italy, the United Kingdom and Spain have embarked on this voyage towards making the necessary arrangements with the aim of bringing about change in the lives of persons with disability. These three countries were among the first EU member states to ratify the Convention and therefore presumably among those who have had the most time to record progress in the implementation of Article 33.

According to Ferri⁴², Italy signed the UNCPRD on 30th March 2007 and ratified it on 15th May 2009 through Law 18/2009. Italy commenced the implementation of Article 33 by designating the Directorate-General for Inclusion and the Directorate for Social Policies as focal point and coordination mechanism respectively. Like many other EU Member States, the focal point designated by Italy with the aim of implementing the Convention is within the internal structure of the Ministry of Labour and Social Policies. It is very probable that this was deemed the most appropriate focal point since it has traditionally been in charge of disability matters. In addition, in order to implement the provisions in Article 33.2 of the Convention, Italy set up the National Observatory on the Situation of Persons with Disabilities to act as independent mechanism to the Convention. The setting up of the Observatory was provided for in Article 3 of Law 18/2009. Ferri⁴³ notes that the Observatory started operating relatively quickly after its setting up, mainly due to the pressure placed by DPOs. It is important to point out that, notwithstanding the fact that the Observatory is newly set up, it is not compliant with the Paris

⁴⁰ Office of the High Commissioner for Human Rights (1993, December) *Principles Relating to the Status of National Institutions (The Paris Principles)*. Retrieved from <http://www.ohchr.org/EN/ProfessionalInterest/Pages/StatusOfNationalInstitutions.aspx>

⁴¹ G. de Beco (ed.) (2013) *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*. Leiden: Martinus Nijhoff Publishers.

⁴² D. Ferri (2013) "Implementation of Article 33 UNCPRD in Italy: Magna Pars est Profectus Velle Proficere," in G. de Beco, ed. *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*. Leiden: Martinus Nijhoff Publishers.

⁴³ Ibid.

Principles but is placed within the Ministry of Labour and Social Policies with financing and chairing of the Observatory both coming from the same Ministry. According to the Law 18/2009 the number of members forming the Observatory should not exceed 40 and must include equal numbers of men and women. Out of the 40 members making up the Observatory there are only fourteen representatives of organizations of persons with disabilities. According to Ferri⁴⁴, in Italy there are a number of DPOs which are active both at national and local level. However, in relation to the provisions of Article 33.3, DPOs are not yet formally involved in the activities organized by the focal points. At the same time, it is worth noting that a number of representatives of DPOs sit on committees and on governmental bodies and thus still play a consultative role at a high level.

The United Kingdom also signed the UNCRPD on 30th March 2007. It ratified the Convention on 8th June 2009. The Office for Disability Issues (ODI) is the designated focal point and coordinating mechanism whilst the four equality and human rights commissions present in the UK are the designated independent mechanisms to the Convention. The ODI is within the internal structures of the Department for Work and Pensions (DWP) and its aim is to draft disability policies as well as to coordinate their implementation across different government departments. The ODI has taken the role of focal point formally but is also aware that there needs to be strong coordination from other government departments in order for the office to continue fulfilling this role responsibly. So far a considerable amount of work by the ODI has been directed towards the drafting of the State Report as required under Article 35 of the UNCRPD⁴⁵. According to Murray and Johnson⁴⁶, the decision to appoint the four commissions, that is, the Equality and Human Rights Commission, the Northern Ireland Human Rights Commission (NIHRC), the Equality Commission for Northern Ireland (ECNI), and the Scottish Human Rights Commission (SHRC) as independent mechanisms was taken with little discussion or consultation with civil society. Notwithstanding the fact that the EHRC has a strong history in

⁴⁴ Ibid.

⁴⁵ R. Murray, & K. Johnson (2013) "Implementation of Article 33 UNUNCRPD in the United Kingdom: The Need to Consolidate Civil Society Engagement," in G. de Beco, ed. *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*. Leiden: Martinus Nijhoff Publishers.

⁴⁶ Ibid.

relation to disability issues, Murray and Johnson⁴⁷ claim that recent restructuring as well as budgetary cuts to the organization will serve to undermine its existence. It is for this reason that Murray and Johnson insist that there should be greater awareness raising about the Convention by disabled people and their organizations. Furthermore, with regards to the provisions of Article 33.3, Murray and Johnson claim that there are concerns about the lack of leadership taken on by the equality and human rights commissions in involving and consulting with persons with disability on translating into actions the provisions in the Convention.

Like Italy and the United Kingdom, Spain was one of the first countries to sign the Convention and the Optional Protocol on 30th March 2007. Both instruments were also ratified in the same year on 3 December 2007, making Spain the first EU Member State to ratify the UNCRPD. In April 2008, the Convention was incorporated into Spain's domestic law, making the Convention stronger over other ordinary laws. The designated focal point of the UNCRPD in Spain is the Directorate-General on Policies to Support Disability within the Ministry of Health, Social Policy and Equality⁴⁸. Bariffi argues that the designated focal point might not have the adequate power to implement the Convention especially in relation to implementing decisions affecting other Ministries. In addition, Bariffi argues that the allocation of the focal point within the Ministry of Health is not a very good decision since it goes against the social model of disability which has clearly been the inspiration for the Convention. The role of the coordination mechanism has been entrusted to the National Disability Council (NDC), which is a collective inter-ministerial body with a consultative role and which is also within the Ministry of Health and Social Policy. With regards to the provisions in Article 33.2, the situation in Spain is known to have been problematic since it transpired that the role of independent mechanism was also entrusted to the NDC. As a result, the Ad Hoc Committee urged Spain to reconsider the appointment of a designated independent mechanism which is in line with the Paris Principles. Following this request, the Spanish government opted to designate the Spanish Committee of

⁴⁷ Ibid.

⁴⁸ F. Bariffi (2013) "Implementation of Article 33 UNCRPD in Spain: A Rather Rrratic and Improvised Experience," in G. de Beco, ed. *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention*. Leiden: Martinus Nijhoff Publishers.

Representatives of Persons with Disabilities (CERMI) as the independent mechanism. This is considered to be a unique and positive decision since it recognizes the direct role of DPOs in the monitoring process. However, uncertainties regarding CERMI's independence and operational funding still prevail. As regards the provisions of Article 33.3, according to Bariffi, there is no record of the involvement of persons with disabilities in relation to the implementation of the Convention at governmental level. Whereas with regards to the NDC, which is the coordination mechanism, there seems to be a more active participation of persons with disabilities since the NDC is composed of 16 representatives of organizations of persons with disabilities with voting rights in the decision making process. In relation to the independent mechanism, compliance with Article 33.3 is covered since CERMI is in fact an umbrella organisation for DPOs.

6. Involving Disabled People in Article 33 in Practice

As can be seen from the experiences of Italy, Spain and the United Kingdom, involving disabled people and their representative organisations in the independent mechanism and in consultation processes is no easy task. Apart from the institutional and structural issues that are encountered, as seen above, this involvement also entails dealing with issues at the most practical levels. This is necessary in order to provide the reasonable accommodation demanded by the UNCRPD itself. In Article 2 (Definitions), the UNCRPD defines reasonable accommodation as follows:

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.

Significantly, this Article also states that failure to provide reasonable accommodation is itself discriminatory. While our focus here is on the provision of reasonable accommodation by human rights bodies entrusted with the protecting, promotion and monitoring of the UNCRPD, the points raised are equally valid both for focal points and other entities entrusted with the

actual implementation of the Convention and other organisations working in the field of human rights.

As seen above, disabling barriers are both cultural as well as material in nature. The provision of reasonable accommodation, aimed at removing material obstacles, means that practical arrangements need to be made to ensure accessibility. Article 9 (Accessibility) of the UNCRPD provides clear and detailed guidance as to the nature of accessibility. It means ensuring ‘to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications’ (Article 9.1). As seen below, these different aspects of accessibility are all relevant for the work of the independent mechanism.

Persons with disability are often spoken of as a group – this is in line with a rights-based approach that places the onus for change on society and not on the individual with disability. However, ensuring that each individual’s rights are realized also means providing reasonable accommodation that attends to the requirements of individual persons with different physical or mental impairments. These requirements have implications for how and where meetings and other activities are held. Buildings must be accessible to all – both in terms of access to the buildings as well as circulation within the building and access to all facilities within it and access to all the information providing during the meeting. The Accessibility for All Standards (SM 3800: 2015)⁴⁹ are among the various documents that provide detailed guidance in this regard. The American Centre for Universal Design (2005) also provides useful guidance regarding physical access as well as in relation to different aspects of making meetings accessible, including ensuring access to communication and information for people with hearing impairment, with speech disabilities, those with visual impairments, as well as those who use augmentative and alternative means of communication. Issues regarding transport also need to be

⁴⁹ MCAA (2015) *SM 3008: 2015 Accessibility for All in the Built Environment*. Retrieved from <http://mcaa.org/mt/en/development-of-standards>.

taken into consideration in the guidelines provided. Another area where accessibility is important is information and communication technology, including of course the Internet⁵⁰.

Crucially, providing this type of access may mean making changes to the way that meetings are conducted. Just to give a few examples, sign language interpreting requires that speakers do not talk too fast and people using communication aids may need time to put their point across – time that has to be factored into the agenda of the meeting. Deaf persons and their interpreters need to sit facing each other, without the former being cut off from the rest of the meeting. A room which is well lit is very important for people with partial sight and those who lip-read, and for a person who is blind introductions are very important – they help the person orient themselves in the room. People who are on the autism spectrum need to be made to feel comfortable and secure. For wheelchair users, especially those who use power wheelchairs, there needs to be enough room to manoeuvre the wheelchair and to sit around a table. Other aspects of organization need to be factored in that are not typically taken into account. For example, providing information in different formats for those with print disabilities.

Furthermore, while the organisers of meetings or other activities usually simply inform the participants about the time and venue, in the case of some disabled people accessible transport may also need to be provided for them to be able to participate in the first place. This is especially the case for disabled people who do not drive and for whom the use of public transport is not possible. If transport is not provided for such disabled persons, they either have to incur considerable expense through the use of taxis, get someone (usually a family member) to take them to and from meetings, or stay away altogether. These various points may seem like minor, even trivial, details especially when spoken of in relation to the implementation and monitoring of a major international human rights treaty such as the UNCRPD. However, the micro-management of the different aspects of accessibility is extremely important and overlooking them can directly result in the disenfranchisement of certain disabled persons who are prevented

⁵⁰ World Wide Web Consortium 2015. Retrieved from: <https://www.w3.org>

from being involved not because of any lack of ability from their part, but because of a lack of accessibility.

One group of disabled persons for whom significantly different arrangements need to be made are people with intellectual disability. Organisations such as Allies in Self-Advocacy⁵¹ and The Social Care Institute for Excellence⁵² are among the many organisations that provide guidelines in this regard. These arrangements include the provision of assistants to support persons with intellectual disability in various manners, including for example guiding them through a discussion, enabling them to make a contribution themselves, both during meetings and by providing written feedback, and making presentations in seminars and other fora. Furthermore, information must be presented in easy-to-read versions – this includes documents such as agendas, minutes, research and policy papers, and so on. It includes, of course, the UNCRPD itself. A look at an easy-to-read version of the Convention, such as the one produced by the UK Equality and Human Rights Commission⁵³ shows how different the content of the Articles looks. While the substance remains the same, the way it is presented is significantly different from the official version. Therefore, while it is important for people with intellectual disability to be included on committees and in meetings, there may also arise the need from time to time of holding meetings that are specifically designed for them in mind – such as an information session about the various Articles of the UNCRPD.

For a minority of disabled persons, meaningful participation in meetings and other activities may be very difficult to achieve. The small population of people who have profound

⁵¹ Allies in Self-Advocacy (2014) *Accessible Meetings and Presentations*. Retrieved from <http://alliesinselfadvocacy.org/accessible-meetings-presentations/>

⁵² The Social Care Institute for Excellence (2015, March 19) *Making Meetings Accessible for People with Learning Difficulties* (easy read). Retrieved from <http://www.scie.org.uk/news/opinion/making-meetings-accessible-people-with-learning-difficulties.asp>

⁵³ Equality and Human Rights Commission (2010) *The United Nations Convention on the Rights of Persons with Disabilities. What Does It Mean For You?* (Easy read). UK: Equality and Human Rights Commission. Retrieved from http://www.equalityhumanrights.com/sites/default/files/documents/publications/unUNCRPD_guide_easyread.pdf

intellectual disability which is often accompanied by additional physical and sensory disabilities can usually only express themselves in relation to their immediate environment and the activities they are directly engaged in – for example expressing preference for certain types of food or drink, or choosing whether to sleep, play or watch television. While in Article 12, the UNCRPD grants legal capacity to *all* disabled people, in some exceptional cases disabled people need a great deal of support to exercise that capacity. It is important also for the interests and wishes of this population group to be represented, whether it is done directly or through those people who live and work most closely with them.

Participation in decision-making processes is not an all-or-nothing affair. Just like anybody else, disabled people have different abilities and aptitudes. They also have the potential to develop their abilities and skills in participation in decision-making. Hart's⁵⁴ participation ladder, which was originally devised for the involvement of young people in decision-making, provides a very useful metaphor of how disabled people's participation can evolve from being passive to becoming increasingly more active. The same metaphor can be used to describe the way disabled people's participation skills can evolve from the most basic everyday decisions to higher order ones, from deciding what to wear to deciding what type of independent living services ought to be provided by the state and other service-providers. Very importantly, non-disabled people who are involved in the work carried out by the bodies appointed through Article 33 also need to climb the participation ladder, albeit following a progression that is in reverse order to that of disabled people. This is because they need to learn and to evolve the skills and disposition to enable disabled people's participation by providing reasonable accommodation in its various forms and guises, and by being willing to take a step back to allow disabled people's own views and perspectives to come to the fore. And, for this to happen, disabled people must be seen as being agents in their own lives, of being able to exercise their legal capacity, and of having the potential to develop further their autonomy regardless of the severity of their impairments. In this way, it is not only material but also cultural barriers that are removed.

⁵⁴ P. McNeilly, G. Macdonald, & B. Kelly (2015) "The Participation of Disabled Children and Young People: A Social Justice Perspective," *Child Care in Practice*, Vol.21. No. 3., pp.266-286.

The examples presented above in relation to catering for various impairment-related requirements are by no means comprehensive. They are meant to highlight the importance of attending to the practical aspects of implementing the principle of ‘Nothing about us without us’. This is because the inclusion of DPOs in independent mechanisms, such as in the three examples presented in the previous section, remains merely symbolic if these seemingly mundane arrangements are not in place.

A final point regarding practical arrangements regards the use of language. It is important that references to disabled persons are made in ways that do not cause offence. This is an area that can be fraught with difficulties. While the term ‘handicapped’ immediately jars on the ears of an English-speaking audience or readership, speaking and writing about ‘le handicap’ in French is perfectly acceptable. And should one say disabled people or persons with disability/disabilities? Is the term ‘special needs’ offensive, or isn’t it? Fortunately, there are documents that provide the necessary guidance, for example the Commission for the Rights of Persons with Disability’s publication titled *Rights Not Charity/Drittijiet Mhux Karita*⁵⁵ which provide guidance to acceptable and unacceptable terms in English and Maltese respectively, and terms whose acceptability is debatable.

7. Disabled People Monitoring the Implementation of the UNCRPD

The best way of ensuring that the different aspects of reasonable accommodation and accessibility are properly taken into account is for disabled people to play an active role in human rights bodies, whatever their remit, but especially those which are specifically part of a country’s independent mechanism that has been entrusted with protecting, promoting and monitoring the implementation of the UNCRPD. This is in line with the disabled people’s movement’s rallying call of ‘nothing about us without us’, and in line with the active involvement of disabled people and DPOs in the drafting of the text of the UNCRPD. The presence of disabled people at all levels and stages of decision-making is also crucial for various

⁵⁵ Commission for the Rights of Persons with Disability (2007) *Rights Not Charity/Drittijiet Mhux Karita*. Malta: Commission for the Rights of Persons with Disability.

reasons. At a practical level, it ensures that taking measures to ensure accessibility becomes an integral part of how the independent mechanism conducts its meetings and its work. It also ensures that it is disabled people's perspectives that are given primary importance and that the independent mechanism shapes its agenda around what is important for disabled people themselves. Finally, and very importantly, it fosters a human rights culture within the independent mechanism itself, a culture which the human rights bodies involved can then strive to foster among legislators, decision-makers, service-providers, employers and in society in general.

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