



Údarás Náisiúnta Míchumais  
National Disability Authority

**A review of Disabled Persons Organisations  
(DPOs) and their participation in implementing  
and monitoring the UNCRPD**

**National Disability Authority (NDA)**

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## Executive Summary

The purpose of the international human rights and development treaty, the UN Convention on the Rights of Persons with Disabilities (CRPD) is to ensure that countries uphold the rights of persons with disabilities and facilitate their full societal participation. To achieve this, the CRPD asks countries to engage persons with disabilities and their representative organisations, Disabled Person's Organisations (DPOs), in CRPD implementation and its monitoring. It believes that this participation will be central to successful CRPD implementation.

DPOs are civil society organisations **of** persons with disabilities as distinct from other disability organisations and charities **for** persons with disability. The CRPD emphasises that for an organisation to qualify as a DPO, it must be (largely) an organisation of persons with a disability where a majority of persons with disabilities form the management, staff, members, volunteers and user groups.

The purpose of this review paper, based on a review of international literature on DPOs including a review of General Comment number 7 and other documentation from the UNCRPD Committee, is to:

- Explore the nature of Disabled Person's Organisations (DPOs) and their participation in CRPD implementation and monitoring globally
- Highlight issues around the participation of DPOs in the legislative and policy processes required to implement the CRPD
- Examine factors that can foster effective participation of DPOs and persons with disabilities in implementing and monitoring implementation of the CRPD
- Provide information on how DPOs are supported to participate in CRPD implementation
- Give some examples of how DPO participation can bring added value and meaningful change in terms of attaining rights and full societal participation for persons with disabilities

A draft of this research report was developed in 2020 and was used to develop a working paper on Engagement with DPOs published in October 2020.<sup>1</sup> This research report has been updated to some extent with the main developments relating to DPOs and legislation relating to the UNCRPD in Ireland in 2020 and

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<sup>1</sup> NDA Working Paper on Engagement with DPOs <https://nda.ie/publications/others/uncrpd/nda-working-paper-on-engagement-with-disabled-persons-organisations.html>

2021 but a review of the international literature for these years has not been conducted.

The CRPD vision is that of participatory democracies where representative DPOs embrace their role as rights advocates and actively engage in implementing and monitoring CRPD implementation. However, in many cases this reality must be worked towards step by step. Each country has its' own constellation of issues that facilitate or slow down implementation of the CRPD principles and articles. These issues must be identified and tackled.

In 2016, the Special Rapporteur on the rights of persons with disabilities, established in 2014 by the Human Rights Council to help countries create an enabling framework for DPOs, suggested that a strategic response by governments might include drawing up a policy framework for DPOs by undertaking the following:

- Review existing legislation
- Provide financial and other support for DPOs
- Establish a formal mechanism, recognized by law, which allows DPOs to register as legal entities

Findings from the literature examined as part of this review included studies that interviewed people in different countries and parts of the world. There was agreement on factors that promote the effective participation of persons with disabilities and DPOs, which include the following:

- Finding and supporting efforts to give a voice to persons with disabilities including those who are not members of umbrella DPOs
- Provision of education/capacity-building for DPOs in human rights, public policy and law, and evaluating the effectiveness of training. DPOs need to acquire knowledge about CRPD implications, understand how to use regional and international monitoring processes and acquire the skills to participate in CRPD monitoring and implementation
- Awareness building and education for government departments and public bodies on accessible meeting techniques and transparent and accessible information and communication
- Financial support for DPOs to participate in public processes on disability issues
- Independent funding for DPO involvement in CRPD monitoring, which may include collecting disability data for parallel reporting
- DPOs establishing good working relationships and networks with politicians and other stakeholders

- DPOs collaborating and cooperating among themselves including umbrella DPOs and building alliances with other human rights NGOs
- In addition to disability specific initiatives, DPOs can monitor and proactively request participation in relevant mainstream initiatives and developments
- DPOs providing decision-makers with evidence-based information to influence decisions and outcomes

## Conclusion

While there is considerable latitude in how States implement the CPRD, the beginning of the path toward effective implementation is to engage the interest and commitment of the whole of government, public services and civil society in implementing the CRPD through a range of mechanisms. Some reports have highlighted that while their countries have made formal positive changes to laws and policies, they have not put them into practice. In this regard, the Office of the United Nations High Commissioner for Human Rights (UN-OHCHR) has stressed the importance of implementing the spirit of the CRPD by translating its Principles and Articles into practice and allowing the goal of societal participation to guide all decisions regarding CRPD implementation.

Ireland has less developed DPO infrastructure than some countries and needs to build same, which may include long term sustainable funding for DPOs. As part of this programme it may be helpful if criteria are developed on how to classify an organisation as a DPO, based on General Comment 7.<sup>2</sup> The proposed development of CRPD strategy, and the plan to replace the NDIS, provides an opportunity to review and improve the approach to supporting and including DPOs and persons with disabilities.

Research has shown that DPOs are most effective when they collaborate and cooperate with each other and speak with one voice on issues of mutual interest. Working with other civil society organisations, they can promote implementation of CRPD Articles and Principles. There are countries whose laws and regulations deny the legal capacity of persons with intellectual disabilities and do not give legal status to self-advocacy DPOs. Umbrella DPOs, in the spirit of the CRPD, can accept all DPOs as members to ensure that they are representative of all persons with a disability. Including self-advocates with intellectual disabilities as

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<sup>2</sup> The New Zealand (NZ) DPO Coalition developed a checklist of attributes they considered an organisation should have to qualify as a DPO (Appendix I). Organisations in NZ can use the checklist to identify what they need to develop to be recognised as a DPO. The NZ DPO coalition use these criteria when evaluating whether to award an organisation DPO status.

full members of DPOs requires adapting formats and processes to meet their needs and providing the training that is necessary for them so that they can participate effectively. Capacity building within DPOs can help them to work more strategically to support CRPD implementation. In many countries, DPOs promote knowledge of the CRPD among their members by organising conferences, holding round tables on CRPD issues, distributing brochures and articles, and through their contact with trade unions and professional organisations interested in CRPD implementation.

## Main Report

### Introduction

The UN Convention<sup>3</sup> on the Rights of Persons with Disabilities (UNCRPD and abbreviated to CRPD and the Convention) is an international human rights treaty adopted by the UN in 2006. It recognises, reaffirms and guarantees the rights set out in the Universal Declaration of Human Rights. It confirms that persons with disabilities are equal to other persons as their rights are the same under the CRPD as under other human rights instruments. It protects the rights and dignity of persons with disabilities. It aims to ensure that states put in place the mechanisms that will uphold their rights. It seeks to empower persons with disabilities, individually and through Disabled Person's Organisations (DPOs), to participate in attaining societal participation through implementing the CRPD. The CRPD specifies that, in addition to DPOs, umbrella DPOs or other bodies set up by a state, persons with disabilities should be able to participate in the monitoring process if they wish.

DPOs are civil society (third sector) organisations **of** persons with disabilities as distinct from disability charities and other disability organisations **for** persons with disability. General Comment No. 7 from the UN Committee on the Rights of persons with disabilities (CRPD Committee) distinguishes DPOs, which are organisations “of” persons with disabilities, from organizations “for” persons with disabilities that provide services or advocate for persons with disabilities. In a DPO, persons with disabilities govern, lead and operate the DPO and form a majority of persons in the DPO. (The UNCRPD Committee is a body of independent experts set up to monitor CRPD implementation.)

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<sup>3</sup> A 'convention' is a formal agreement between States. The generic term 'convention' is thus synonymous with the generic term 'treaty' <https://www.unicef.org/french/crc/files/Definitions.pdf>

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Note: A draft of this research report was developed in 2020 and used to develop a working paper on Engagement with DPOs published in October 2020. This research report has been updated to some extent with the main developments relating to DPOs and legislation relating to the UNCRPD in Ireland in 2020 and 2021 but a review of the international literature for these years has not been conducted.

After adopting the CRPD in 2006, the UN opened it for signature and ratification in 2007. In 2008, after 20 countries had ratified it, it entered into force. By ratifying the CRPD, countries make a commitment in international law to translate its principles into policy and practice. The Irish Government ratified the CRPD in 2018.<sup>4</sup> Before ratifying the CRPD, the Irish government worked at bringing some legislation into line with the CRPD, which delayed its ratification. In effect, Ireland identified ratification as the end of a review process rather than its beginning.<sup>5</sup> The 'Roadmap to Ratification' published by the Department of

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<sup>4</sup> Ireland has committed to ratifying the CRPD Optional Protocol after completing the first CRPD reporting cycle if not sooner. The Optional Protocol is a complimentary enforcement mechanism to the CRPD, allowing individuals to make complaints at the CRPD Committee on the violations of their rights as guaranteed under the CRPD. It allows the CRPD committee to make systemic inquiries into rights violations in that country. It equips persons with disabilities, as individuals and as groups, with new avenues to seek justice and defend their rights.

<sup>5</sup> Deaglán Ó Briain on beginning to account for the UNCRPD in Irish legislation [https://www.eud.eu/files/1814/7393/7249/Debrief\\_ERA\\_UNCRPD\\_seminar\\_-\\_for\\_website.pdf](https://www.eud.eu/files/1814/7393/7249/Debrief_ERA_UNCRPD_seminar_-_for_website.pdf)



Justice and Equality in Ireland identified many provisions of various legislation that needed amendment before ratification could happen.<sup>6</sup>

The Irish government introduced capacity legislation in line with the CRPD: The Assisted Decision Making (Capacity) Act 2015 (ADMA), signed into law on the 30 December 2015, applies to everyone and is relevant to health and social care services. The act is about maximising a person's capacity to make decisions by supporting decision-making. The government has not yet fully commenced the act and amending legislation is currently being developed. It is expected that the amended Act will commence in June 2022. A Disability (Miscellaneous Provisions) Bill 2016 included a series of provisions to ensure that Ireland fully implements the CRPD. This Bill fell with the dissolution of the Dail in mid-2020. Many of its provisions have been incorporated into the revised ADMA Act.

The report provides a brief history of DPOs in section 1. It then looks at DPO participation in CRPD monitoring and implementation in section 2. In section 3 it examines how DPOs are financed in other jurisdictions. Section 4 examines factors promoting effective DPOs. Section 5 looks at disability structures and participation in Ireland. The report finishes with a conclusion section. In addition there are detailed appendices giving more details on various issues relating to DPOs and proving a number of case studies related to DPO involvement in UNCRPD implementation.

## **1.0. A brief overview of the history of DPOs**

Disability advocates throughout the world, like other minority groups, learned from the 1960s civil rights movement in the USA and demanded equal treatment, access and opportunity. However, prior to the 1970s, the views of persons with disability were still filtered through the voices of disability service providers and family members. In the 1970s, disability rights activists in the USA lobbied Congress to include civil rights language in the 1973 Rehabilitation Act, which, for the first time in history, saw the law protecting the civil rights of persons with disabilities. The non-legally binding 1975 UN Declaration of the Rights of Disabled People, provided a framework globally for the equal treatment of persons with disabilities. De-institutionalisation began and the disability movement<sup>7</sup> promoted the formation of grassroots DPOs.

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<https://www.justice.ie/en/JELR/Roadmap%20to%20Ratification%20of%20CRPD.pdf/Files/Roadmap%20to%20Ratification%20of%20CRPD.pdf>

<sup>7</sup> There is no agreement on how to define the term 'disability movement', or on where its boundaries lie, or on what it means to its members. It often means an alliance of DPOs and, depending on the national and international contexts, such DPOs may represent one or more of

The first international DPO was established in 1980. Rehabilitation International, the global organization on disability and rehabilitation issues, had a policy that persons with disability could attend their conferences as observers but could not speak. At their 1980 international conference in Winnipeg, persons with disabilities protested against the policy. It was there that the concept of an international DPO emerged and Disabled People International (DPI) was formed. The following year, 1981, the International Year of Disabled People led to the adoption of a UN World Programme of Action concerning Disabled Persons, which emphasised approaching disability issues from a human rights perspective. DPI held its first World Congress in Singapore in 1981 and the following year, the United Nations announced the UN Decade of Disabled Persons (1983-1992).<sup>8</sup>

In the UK, DPOs experienced significant growth and diversification through several decades. They have had a major impact on redefining independent living, inclusion and social care and in diverting local authority funding from residential care to DPOs for community support options. The National Centre for Independent Living focused on lobbying government on direct payments, which was put on the statute books through the Community Care (Direct Payments) Act in 1996. The growth of the independent living movement in the UK eventually led to the introduction of the personalisation agenda and social care reform. The UK Personalisation Agenda encouraged DPOs to become service delivery structures and awarded contracts to DPOs to deliver direct payment support services. This led to growth and sustainability for DPOs and to their professionalization. Some DPOs became major budget holders. Across the UK there are large differences in how DPOs are used by local government. Some local government areas deliver many services through DPOs while others have no such activity.

The European Network on Independent Living (ENIL) was formed in 1989. In April 1989 at the European Parliament in Strasbourg more than 80 persons with extensive disabilities from two dozen countries participated in a 3 day conference on personal assistance. During this event ENIL was founded. The themes that form the activity areas and demands of ENIL to the present were

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the following groups: people with physical impairments, people with visual impairments, deaf people, people with hearing impairments, people with intellectual disabilities, autistic people, etc. Not all persons with disabilities have an equally strong voice in the disability movement, in particular, persons with intellectual disability and autism. The disability movement has an international structure and, in some countries, national and local level structures that facilitate society hearing and supporting the voice of persons with disabilities

<sup>8</sup> The role and position of DPOs in community based rehabilitation: balancing between divided lines [https://www.dinf.ne.jp/doc/english/asia/resource/apdrj/vol20\\_1/guest-ed.html](https://www.dinf.ne.jp/doc/english/asia/resource/apdrj/vol20_1/guest-ed.html)

formulated then: anti-discrimination, de-medicalisation, de-institutionalisation, de-professionalization, taking control of disabled people's organisations, self-management of services, peer counselling, personal assistance and empowerment. The ENIL Independent Living Principles were adopted in 1990. The global Independent Living network, called for in Strasbourg in 1989 came to life in 2017, when the World Network of Centers of Independent Living (WIN) was established in Washington DC.<sup>9</sup>

Blackmore and Hodgkins (2012) point out, however, how DPOs can be gradually absorbed into service delivery structures and can lose their independent voice and position as human rights organisations or part of a disability movement.<sup>10</sup> In addition, rapid changes in funding and differences between central and local government policy, can make it difficult for DPOs to survive. Professional, large DPOs, often companies limited by guarantee, can access various funding streams and employ paid staff and are, therefore, often able to adapt to constant change and survive better than small DPOs.

The 2006 UNCRPD was the culmination of decades of work by the UN. It is a human rights instrument with an explicit, social development dimension. Ratification of the CRPD is a binding instrument on governments to ensure the protection of human rights for all their citizens with disabilities. The CRPD presents multiple opportunities for DPOs to engage in advocacy at all levels, including national implementation of the CRPD and engaging with the human rights and sustainable development processes.

DPOs vary from small community groups to international NGOs with bases in many countries. Some DPOs represent a particular group, e.g. people living with cerebral palsy or persons with intellectual disability. Other DPOs represent population groups and their experience of disability, e.g. women with disability. Cross-disability DPOs attempt to represent the interests of all persons with disability. DPOs may offer advocacy, service provision and social support.

Research illustrates that, globally, DPOs have helped people with disabilities attain wider societal participation, supported capacity building and leadership, and worked with public authorities to improve inclusion in practice. For example, DPOs in Egypt played an active role in shaping Egypt's new constitution in 2014. As a result the Constitution includes an article on the rights of persons with

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<sup>9</sup> <https://enil.eu/news/30-years-of-the-european-network-on-independent-living/>

<sup>10</sup> Blackmore, T., Hodgkins, SL (2012) Discourses of DPOs: Foucault, Bourdieu and Future Perspectives. In: Disability and Social Theory: New developments and directions Editors: Dan Goodley, Bill Hughes and Leonard Davis. Palgrave (London)

disabilities, while separate articles outline the rights of children with disabilities and establish the National Council of Disability Affairs.<sup>11</sup> Similarly, DPOs engaged in constitutional reform processes in Uganda and South Africa both of which adopted strong protection for disability rights. Even without constitutional protection, DPOs and person with disabilities press for their rights through litigation and advocacy. In countries that have ratified the CRPD, DPOs and other civil society groups have used the CRPD to help drive improvements in accessibility in areas such as education, workplaces, public spaces, legislature, etc.<sup>12</sup>

In Iceland, the collaborative involvement of DPOs led to significant changes to draft legislation on Personal Assistants and other legislative changes on DPO participation.<sup>13</sup> However, DPOs have also had to fight to prevent the rolling back of gains made. In other countries, where collaborative practices are difficult, DPOs and persons with disabilities have pressed for change through litigation and advocacy.<sup>14</sup>

In Belgium, a DPO, Onafhankelijk Leven (OL) is the ‘Independent Living movement in Flanders’. It has taken an active part in co-producing the Personal Assistance scheme for Flanders. It also provides services. As a member of the Advisory Committee organised by the Flemish Agency for People with Disabilities, it has provided input on Personal Assistance, reimbursement of assistive technology, house and car adaptations and other issues.<sup>15</sup> In South India, the joint effort of DPOs helped to successfully fight corruption at pension pay-out points.<sup>16</sup> In the UK, DPOs have championed the implementation of personalised supports and their work influenced the design of the 2007 Putting

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<sup>11</sup> Sprague, A., Raub, A., Heymann, J. (2020) *Advancing Equality: How constitutional rights can make a difference* University of California Press and <https://rethinkingdisability.net/a-new-legislation-for-the-egyptian-persons-with-disabilities-hopes-and-fears/>

<sup>12</sup> *ibid*

<sup>13</sup> The Organization of Disabled in Iceland (ÖBÍ), is the national DPO with 33 member DPOs. It represents persons with disabilities and works to safeguard their interests, for example regarding legislation and the implementation of law and regulations. The organization provides consultation for persons with disabilities and their relatives. It an active participant with DPOs abroad and is a member of the European Disability Forum (EDF).

<sup>14</sup> Löve, L., Traustadóttir, R., Rice, J (2019) *Shifting the Balance of Power: The Strategic Use of the CRPD by Persons with disabilities’s Organizations in Securing ‘a Seat at the Table’*

<sup>15</sup> *Implementing Article 4(3) of the UN Convention on the Rights of Persons with Disabilities* [http://enil.eu/wp-content/uploads/2016/06/Fact-Sheet\\_Article4\\_FINAL.pdf](http://enil.eu/wp-content/uploads/2016/06/Fact-Sheet_Article4_FINAL.pdf)

<sup>16</sup> *The role and position of DPOs in community based rehabilitation: balancing between divided lines* [https://www.dinf.ne.jp/doc/english/asia/resource/apdrj/vol20\\_1/guest-ed.html](https://www.dinf.ne.jp/doc/english/asia/resource/apdrj/vol20_1/guest-ed.html)

People First programme, which included Direct Payments and Personal Budgets, and which the Directors of Adult Social Services in Local Authorities and the Department of Health deliver in some areas through DPOs. Representatives from the majority of the DPOs in the New Zealand DPO Coalition were involved in negotiations on the drafting of the CRPD as were DPOs from other countries. In low and middle income countries, research found some positive outcomes associated with the work of DPOs in terms of employment rates; access to microfinance and bank loans; housing accessibility; acquisition of orthopaedic devices; involvement in civil society; development of friendships and networks; and participation in training programmes.<sup>17</sup>

From lived experience, DPOs are familiar with the needs, aspirations and abilities of persons with disabilities. They can create public awareness about them in multiple ways: lobbying governments, monitoring disability services and supports, using national, local and social media opportunities, attending conferences, publishing material on disability issues and implementing and monitoring the CRPD. DPOs can provide persons with disabilities with voices of their own, identify their needs, express their views on priorities, evaluate services, advocate for change and raise public awareness. With the advent of the CRPD, DPOs are increasingly engaging at local, national and international levels.

Appendix 2 examines persons with disabilities and DPO involvement in CRPD implementation and has a number of case studies including New Zealand, Iceland and Malta.

## **2.0. CRPD and DPO participation**

The CRPD places the participation of persons with disabilities and their representative organizations, DPOs, at the heart of CRPD implementation.. It is the first UN treaty to include representatives of the potential beneficiaries of the treaty as equal partners with governments in negotiating the implementation of its principles and articles.<sup>18</sup> It has been suggested that with more than one billion persons with disabilities worldwide, if States remove all barriers to participation, the positive impact of persons with disabilities and their contribution to society is potentially significant.<sup>19</sup> CRPD implementation is a unique opportunity to improve the quality of life of persons with disabilities. In parallel with the development of

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<sup>17</sup> Young, R., Reeve, M., Grills, N. (2016) The Functions of DPOs in Low and Middle-income Countries: A Literature Review. *Disability, CBR & Inclusive Development*, [S.l.], 27 (3), p. 45-71,

<sup>18</sup> Mittler, P (2015) The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift, *Journal of Policy and Practice in Intellectual Disabilities* 12 (2), p. 79–89

<sup>19</sup> United Nations Secretary-General Ban Ki-moon, message on the occasion of the International Day of Persons with Disabilities, 3 December 2012 as cited by Mittler, P (2015)

the UN Sustainable Development Goals (SDGs),<sup>20</sup> the CRPD asks for a reappraisal of policy and practice by governments, service planners and providers, professional and voluntary organizations, the research community, and society as a whole.

The CRPD addresses participation as a crosscutting issue in its preamble and in its purpose (Art. 1). Full and effective participation and inclusion in society is one of the general principles underpinning the CRPD (Art. 3). Participation in political and public life is articulated as a right (Art. 29). As a political right, according to Article 29, countries must promote the establishment of DPOs to represent persons with disabilities at international, national, regional and local levels. Participation is also central to the Articles on implementation and monitoring mechanisms (Arts. 4, 33, 34 and 35) and international cooperation (Art. 32). Participation is there in relation to the right to independent living and being included in the community (Art. 19), inclusive education (Art. 24), rehabilitation, etc. (Art. 26) and cultural life, recreation, leisure and sport (Art 30). The concept is present in the article on children with disabilities (Art. 7), and in articles that prescribe prerequisites for enabling participation such as accessibility (Art. 9), freedom of expression and opinion, and access to information (Art. 21). Appendix 3 contains a list of all the articles of the CRPD.

Article 4.3 specifies that States Parties involve persons with disabilities through their DPOs while Article 33 outlines how the oversight and independent monitoring of CRPD implementation should involve the direct participation of DPOs and/or persons with disabilities.<sup>21</sup> The primary obligation for a State Party under Article 33 is to put in place a structural framework including an independent mechanism that promotes, protects and monitors CRPD implementation at the national level. This framework is at the heart of driving a positive dynamic of reform so that countries can meet their obligations under the CRPD. The CRPD committee expects that governments, agencies and institutions will pro-actively seek out the help of DPOs and find the best ways to support their participation in the Article 33 structure. The involvement and expertise of DPOs are key to the work of the independent mechanisms (IHREC

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<sup>20</sup> The seventeen UN Sustainable Development Goals (SDGs), launched in September 2015, provide a framework for sustainable and responsible practices. The 17 interconnected goals address global challenges and provide a blueprint on how to improve the planet and the lives of its citizens by 2030 by achieving sustainable development. The SDGs build on the Millennium Development Goals (MDGs) set by the UN in 2000 until the end of 2015.

<sup>21</sup> Page v, Emily Logan, Chief Commissioner, Irish Human Rights and Equality Commission, in the foreword to the 2016 Report, 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of persons with disabilities' produced by the Centre for Disability Law and Policy School of Law & Institute for Life-course and Society, NUI Galway

in Ireland) as the voice of persons with disabilities are essential. Apart from the independent mechanism, Article 33 outlines the need for the full participation of DPOs in the monitoring process.<sup>22</sup> Appendix 4 contains further information on Articles 4.3 and Article 33.

One cannot assume that the voice of a DPO or DPOs necessarily represents the views of persons with disabilities in all cases. For example, where DPOs act as care and service providers, they may represent professional interests as well as the interests of persons with disabilities. They may be compromised or feel that way in order to ensure continued funding for the services they provide. Some DPOs may represent the views of families, whose viewpoints and priorities may not always coincide with those of individual persons with disabilities.

In some countries, there has been historical confusion between organizations of disabled people advocating for their rights and organizations providing services for persons with disabilities who simultaneously advocate for their rights or claim to do so. In France, to address this issue, some organizations split into two with a service provider and advocacy arm and separate governance structures under the same umbrella organization. However, while the need to have equal representation between service provider organisations and advocacy and rights organisations has been raised and debated in France, the law states that DPOs should be represented alongside associations representing service providers. As a result, non-service provider DPOs are still a minority in consultative bodies. In France, the National Consultative Council of Disabled People and Local Consultative Councils of Disabled People have existed since 2002. DPOs account for one third of these councils alongside a third comprising services and local government and another third composed of experts nominated by the prefects at the local level.<sup>23</sup>

The Special Rapporteur on the rights of persons with disabilities published a report in January 2016 on promoting and protecting human rights.<sup>24</sup> This report notes that establishing stable and enabling environments for DPOs remains a

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<sup>22</sup> EQUINET (European Network of Equality Bodies) (2018) Engagement of the article 33(2) Independent Monitoring Mechanisms with the UNCRPD Committee and Disabled Persons' Organisations Training event for equality bodies and National Human Rights Institutions Riga, 3-4 October 2018

<sup>23</sup> Sherlaw, W., Hudebine, H (2015) The United Nations Convention on the rights of persons with disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities *European Journal of Disability Research*, 9, 9–21

<sup>24</sup> Report of the Special Rapporteur on the rights of persons with disabilities (January 2016) <https://undocs.org/A/HRC/31/62>

challenge for most countries. It states that the advocacy role of disability service providers needs to be carefully assessed, as it can easily happen that advocates seek to ensure the continuity of services, regardless of whether or not they are human rights-based or the preferred options of persons with disabilities. “The failure of States to acknowledge the distinction between organizations “of” and “for” persons with disabilities lies at the heart of historical tensions between the two types of organization, such as those around legitimacy, choice and control, and the allocation of resources. In their pursuit of genuine participation by persons with disabilities in decision-making processes, States need to ensure that the will and preferences of persons with disabilities themselves are given priority”.<sup>25</sup>

The requirement to involve persons with disabilities and DPOs in implementing and monitoring the CRPD can be challenging for states for a number of reasons. In many cases establishing a well-functioning participatory structure requires a shift in thinking and in organisation to facilitate the full and equal participation of persons with disabilities as stakeholders and change agents, alongside government representatives and other institutions and agencies. Implementing the economic, social and cultural provisions of the CRPD, such as accessibility, reasonable accommodation and the right to cultural life, requires considerable financial investment. In contrast, while ensuring the participation of DPOs and individual persons with disabilities in decision-making may require some financial support, it first requires a change in attitude and clear decisions to work at setting up practical mechanisms that include DPOs and persons with disabilities as essential and valued partners in policy and legislative processes as outlined in the CRPD.<sup>26</sup> Commitment, creativity, collaboration<sup>27</sup> and raising awareness of discrimination<sup>28</sup> is required to ensure that all parties engage in attaining equal rights for persons with disabilities as manifested in full societal participation on an equal basis with their peers.

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<sup>25</sup> <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/004/48/PDF/G1600448.pdf>

<sup>26</sup> Mittler, P (2015) The UN Convention on the Rights of Persons with Disabilities: Implementing a Paradigm Shift, *Journal of Policy and Practice in Intellectual Disabilities* 12 (2), p. 79–89

<sup>27</sup> Making disability rights real in New Zealand. Annual report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities 2011 – 2012  
[file:///H:/Downloads/New%20Zealand\\_Special%20Report%20on%20CRPD%20Monitoring\\_2011\\_2012\\_EN%20\(1\).pdf](file:///H:/Downloads/New%20Zealand_Special%20Report%20on%20CRPD%20Monitoring_2011_2012_EN%20(1).pdf)

<sup>28</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, [https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)



While many States have been ratifying the CRPD for over a decade, they are at different stages of implementation. Analyses of DPO involvement in CRPD implementation show wide variation in how countries are implementing the involvement of DPOs and persons with disabilities, the speed of implementation and how countries are responding to the feedback received from the CRPD committee on the involvement of persons with disabilities and DPOs.

Appendix 2 contains case studies and lays out findings from the literature on DPO involvement and the impact that DPOs can have. The literature reviewed includes the following:

- A 2014 analysis by the European Union Agency for Fundamental Rights (FRA)<sup>29</sup> PhD research by Birtha (2016)<sup>30</sup>
- A 2016 analysis by IHREC (2016) of Article 33 frameworks in six states<sup>31</sup>
- Research (2017) by the German Institute for Human Rights for the Global Alliance of National Human Rights Institutions (GANHRI) on Article 33 frameworks<sup>32</sup>
- A 2018 “gap analysis” by the CRPD Committee between the goal and spirit of articles 4 (3) and 33 (3) and the degree to which State parties implemented them<sup>33</sup>

Appendix 4 contains more detailed information on the CRPD, participation and DPOs including Articles 4 (3) and Article 33. Appendix 5 and 6 consists of the some of the UN Committees recommendations to States on the implementation of Articles 4.3 and 33 including the text of these articles.

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<sup>29</sup> <https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

<sup>30</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>31</sup> IHREC (2016) ‘Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of PERSONS WITH DISABILITIES’  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

<sup>32</sup> Aichele, V in the German Institute of Human Rights (2017) Analysis: Promote, Protect and Monitor 2017 Update Survey on Article 33 (2) of the Convention on the Rights of Persons with Disabilities [https://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/Publikationen/ANALYSE/Analysis\\_Promote\\_\\_Protect\\_\\_and\\_Monitor.pdf](https://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/Publikationen/ANALYSE/Analysis_Promote__Protect__and_Monitor.pdf)

<sup>33</sup> No. 8, General Comment No. 7, Committee on the Rights of persons with disabilities 2018

### 3.0. Factors promoting the effective participation of DPOs

Below is a summary from this review of research papers on the factors that facilitate effective participation and examples of what countries are doing with regards these factors. One can divide factors into those relevant for governments and those that are more relevant for other decision makers or for DPOs and persons with disabilities.<sup>34 35 36 37 38</sup>

Even when DPOs are involved in policy and legislative processes and monitoring CRPD implementation, they may not influence outcomes if their voice is not heard and attended to. Research on effective participation involving respondents from many countries, highlighted factors that respondents considered were prerequisites for effective involvement and regardless of their country of origin, the respondents agreed on many factors that promote effective involvement.<sup>39</sup>

#### Factors for governments and other decision makers to promote effective DPO participation

- Consideration of the financial supports necessary for DPOs to participate in public processes on disability issues, including independent funding for their involvement in CRPD monitoring, which may include collecting disability data for parallel reporting

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<sup>34</sup> <http://www.internationaldisabilityalliance.org/resources/steps-after-ratification>

<sup>35</sup> Birtha, M (2016) Making the new space created in the UN CRPD real  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>36</sup> [https://www.globaldisabilityrightsnow.org/sites/default/files/related-files/345/Guidance\\_Document\\_Effective\\_Use\\_of\\_International\\_Human\\_Rights\\_Monitoring\\_Mechanisms\\_to\\_Protect\\_the\\_Rights\\_of\\_Persons\\_with\\_Disabilities\\_English.pdf](https://www.globaldisabilityrightsnow.org/sites/default/files/related-files/345/Guidance_Document_Effective_Use_of_International_Human_Rights_Monitoring_Mechanisms_to_Protect_the_Rights_of_Persons_with_Disabilities_English.pdf)

<sup>37</sup> Löve, L., Traustadóttir, R., Rice, J (2019) Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing 'a Seat at the Table'  
<https://www.mdpi.com/2075-471X/8/2/11/pdf>

<sup>38</sup> Meyers, S (2016) in NGO-ization and Human Rights Law: The CRPD's Civil Society Mandate  
<https://pdfs.semanticscholar.org/6759/a3818572c7b0218d26ff5cf03160235e9525.pdf>

<sup>39</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)  
In the first phase of this research, interviews with five leaders of the European Disability Forum (EDF) were held In the second phase, the researcher sent questionnaires to the secretariats of 29 national councils that are full national members of EDF. The third phase involved field trips to three countries to collect data.

- Consider establishing active working relationships with DPOs and persons with disabilities and set up formal structures for their participation
- Consider engaging persons with disabilities, for example, as experts on advisory boards, for impact assessments, etc
- Consider supporting effective involvement and participation of civil society, particularly DPOs by committing to, for example:
  - Involving DPOs and/or persons with disabilities from the early-stage of legislative and policy processes - before the government makes decisions - this is the key element of civil society participation
  - Providing or funding education/capacity-building for DPOs in human rights, public policy, and law and ongoing evaluation of capacity building. Capacity building should include marginalized segments of the disability movement in policy and decision- making processes to avoid a fragmented disability movement
  - Supporting efforts to give a voice to all persons with disabilities including those who are not members of umbrella DPOs
- Consider the training of decision-makers such as government departments, public bodies, etc., on meeting techniques, accessibility, transparent and accessible information and communication
- Consider continuous evaluation of the quality and impact of participation of DPOs and persons with disabilities in the relevant policy, legislative and CRPD monitoring processes

### **Factors that facilitate the effective participation of DPOs**

- Umbrella DPOs working together and speaking with one voice on issues of mutual interest to them, enhances their impact on disability issues and on the outcomes attained for persons with disabilities
- Collaboration and strengthening cooperation among DPOs maximizes the impact of their contributions. A range of disability constituencies can lead the national DPO coalition for monitoring the CRPD. However, as the CRPD is a broad instrument, to ensure that all areas are covered, the national CRPD coalition can reach out to and include other civil society organizations that are working on issues covered by the CRPD
- Establishing active working relationships and build networks with politicians and other stakeholders
- Building alliances with human rights NGOs allows DPOs to learn from them and contributes to an increased attention to the rights of persons with disabilities by other organizations

- In addition to disability specific initiatives, DPOs can monitor and proactively request participation in relevant mainstream initiatives and developments
- DPOs can provide decision-makers with evidence-based information to influence decisions and outcomes
- DPOs can acquire more knowledge about the implications of the CRPD, to understand how to use regional and international monitoring processes to support their own advocacy work and to acquire skills needed to participate in implementation and monitoring of the CRPD. They can acquire knowledge on, for example, complaint procedures, advisory services and consideration of disability as a crosscutting issue
- Participate from the beginning and throughout the relevant processes e.g., transparent policy-making processes by government
- Evaluate their participation, e.g., by developing indicators

#### **4.0. Financial supports for DPO participation**

Lack of funding, fluctuations in funding or withdrawal of funding is an issue that DPOs face in many countries. Changes in funding and differences between central and local government policy, can make it difficult for civil society organisations such as DPOs to survive. In times of change, a DPO needs to be able to take advantage of new opportunities. Large, professional DPOs, often companies limited by guarantee, that employ paid staff, are usually better placed than small DPOs to access new and various funding streams and adapt to change. In 2013, Canada moved from its on-going financial support of DPOs to an open competitive process in a Social Development Partnerships Program. In this new approach, organisations tendered for projects to improve the participation and integration of persons with disabilities. However, despite the partnerships and leveraging requirements of the programme, it did not result in increased viability for many DPOs. Organizations that successfully leveraged large financial contributions had better capacity to sustain their projects than most DPOs.

At times of economic austerity, governments often reduce funding to the voluntary and community sector. Another issue of concern raised in the literature is that it may be difficult for DPOs to retain their independent voice as human rights organisations when they become involved in service delivery structures and in political and economic projects of social inclusion.

In addition to funding from governments, DPOs – and perhaps governments or local authorities - could look for funding from international funders and operators who support disability-related issues or who address disability within other thematic areas which are at the core of their particular mission and programme. Disability is a cross-cutting issue that can be addressed from within

any foundation programme supporting, for example, inclusion, education, employment, arts and culture, healthcare, etc.<sup>40</sup>

It is difficult to get detailed information on financial support given for the participation of DPOs and persons with disabilities in CRPD implementation and monitoring. In some countries, governments report on all their financing of disability organisations without distinguishing between DPOs and other charities and organisations **for** persons with disability.

Below are some details of DPO financing currently or in the past in New Zealand, Denmark, England, and Serbia.

### **New Zealand**

New Zealand (NZ) has well established DPOs that actively participated in the formulation of the CRPD. DPOs have been involved in implementing disability strategies for some time before the formulation of the UNCRPD. The 2014 concluding observations of the UNCRPD Committee commended NZ for its implementation of an Independent Monitoring Mechanism (IMM) that was truly independent.

The NZ government funds the Human Rights Commission and the Office of the Ombudsman to execute their CRPD responsibilities. The Office for Disability Issues (ODI) has been the government focal point on disability since its establishment in 2002 under the NZ Disability Strategy. The ODI funds DPOs from two funding streams.

One funding stream is for a DPO coalition to enable DPOs to work as a coalition, provide collective advice to the government and engage in the governance of the Disability Action plan alongside government officials. Funding for the coalition, established in 2012, has enabled seven DPOs to work together to provide advice to the government. It partners with the government to develop the Disability Action Plan (DAP) and it governs the DAP together with government officials. Funding received covers meetings, meeting fees and costs such as secretariat support and Sign Language interpreters, travel and accommodation. Actual annual spend varies depending on the number of meetings etc. Since 2015/2016, ~\$100,000 (€57,500) to \$120,000 (€69,000) has been budgeted annually.

A second funding stream from the ODI is for a Convention Coalition Monitoring Group (CCMG) that draws its members from the DPO coalition. An umbrella

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<sup>40</sup> See, for example, Institutional philanthropy - a focus on disability what EFC (European Foundation Centre) members and other philanthropic organisations are doing in the field of disability (2019) [https://www.efc.be/uploads/2019/10/DisabilityMapping\\_online.pdf](https://www.efc.be/uploads/2019/10/DisabilityMapping_online.pdf)

group of representatives from national DPOs, the CCMG was set up in 2010 to govern the disabled-people-led monitoring component of the UNCRPD Independent Monitoring Mechanism (IMM). It forms part of the tripartite monitoring framework, which consists of the Office of the Ombudsman, an NHRI (the Human Rights Commission) and the CCMG. ODI funds a contract with the CCMG to monitor implementation of the CRPD. The CCMG coordinates a mechanism for the input of persons with a disability into monitoring disability rights. The CCMG conducts a qualitative research and monitoring programme including collecting evidence from persons with a disability. The CCMG informs the IMM through formal monitoring reports and through participation in quarterly IMM meetings and IMM working group meetings.

The 2017/2018 spend of the CCMG was €94,000. Some further funding figures for DPOs in NZ are available in appendix 2.<sup>41</sup>

### **Denmark**

The national umbrella Disabled Peoples Organisation (DPOD) in Denmark has 33 member organisations. Members of parliament can consult DPOD for advice on disability matters. DPOD has been involved in legislative processes to implement the CRPD through informal and formal contacts and through meetings with civil servants, ministers, members of Parliament, writing bilateral letters, and using mass media. CRPD feedback in 2014 on Denmark's initial report noted the operation of the State party's Inter-ministerial Committee but expressed concern that government seeks inputs from DPOs in Denmark only occasionally.

In terms of CRPD monitoring in Denmark, DPOD received ~€120,000 from the government in 2012 to cover the cost of coordinating and drafting the alternative civil society report on the implementation of the CRPD for Denmark's initial CRPD review.<sup>42</sup>

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<sup>41</sup> Letter from the Ministry of Social Development, NZ, in response to an email request relating to Maori with disabilities. The questions included one on the funding provided to DPOs for their participation in the International Monitoring Mechanism for the UNCRPD each year for the past five years <https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/official-information-responses/2019/march/r-20190326-implementation-of-ministerial-priorities-on-disability-issues-for-maori-details-regarding-fundings-provided-to-dpos-dpo-representatives-for-the-past-five-years.pdf>

<sup>42</sup> p. 135, Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

DPOD works with the Ministry of Foreign Affairs of Denmark to support disability movements in developing countries capable of advancing CRPD implementation. The 2018 Danish Finance Act states that projects implemented **directly** by DPOD should support activities in the global South.<sup>43</sup> This is in line with CRPD Article 32 on international cooperation, which states that States Parties to the CRPD have a duty to evaluate their development aid programmes from the perspective of the CRPD. Ideally, countries would proactively mainstream disability into their development programmes and consider programmes that target persons with disabilities as the primary beneficiary. In its 2014 feedback on Denmark's initial CRPD report, the CRPD Committee commended it on its exemplary role in international development assistance and on the integration of a disability policy perspective therein,

Until 2017, the Danish Ministry of Foreign Affairs supported DPOD through a Framework Agreement (€975,000 in 2017) and a Disability Fund managed by DPOD (€4.3 million in 2017) from which DPODs Danish member organisations obtain funding for development interventions in the developing world. Starting from January 2018 the Danish Ministry provided DPOD support under one consolidated grant (€5.7 million), which DPOD operated as fund administrator and implementer of its own projects and programmes.

## England

In England, in 2006, the Office for Disability Issues in the Department for Work and Pensions sponsored a non-statutory Advisory Non-Departmental Public Body (NDPB) called Equality 2025. This body comprised nine publically elected persons with disabilities responsible to the Minister for Disabled People. Their role was to provide strategic confidential advice to government on the issues that affect persons with disabilities. Group members received pay for their work and the financial allocation for the group was up to £400,000 per annum. The 2010-2015 UK Government reviewed Equality 2025 and, because of the review, disbanded the NDPB in 2012.<sup>44</sup> The review considered that it could not provide strategic expert advice to government in all subject areas. It recommended an expertise model to deliver strategic advice and either strategic partnerships with disability organisations or an expert ad hoc advisory group to engage with

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<sup>43</sup> Restricted procedure: Review of the Disabled People's Organisations Denmark (DPOD) <https://um.dk/en/about-us/procurement/contracts/short/contract-opportunities/newsdisplay>

<sup>44</sup> Watts, R (2013) An independent review of Equality 2025 (Advisory Non Departmental Public Body) For the Department for Work and Pensions [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/320800/independent-review-of-equality-2025.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/320800/independent-review-of-equality-2025.pdf)

persons with disabilities. The review considered that either of these options would demonstrate commitment to engaging with persons with disabilities.

Successive governments supported DPOs until 2015 but since then there has been no central government funding to develop DPOs. DPOs were thus dependent on local funding bodies, who have no statutory requirement to engage with or fund DPOs or other such groups in England. While Social Services and Well-being Act 2014 (Wales) requires local authorities to promote the involvement of persons for whom they provide care and support or preventative services, there is no such requirement under the Care Act for English Councils. At the end of 2018, the Office for Disability Issues announced that it would set up a regional stakeholder network to enable persons with disabilities and DPOs to influence government. However, some hold the belief that such stakeholder groups are not a substitute for central funding and do not meet the policy objective of developing DPOs.<sup>45</sup> The number of DPOs has fallen dramatically over a decade in England with the lack of consistent, core funding as a key factor behind closures. Funding cuts experienced by local authorities and health services are a reason for this as, for example, local authorities have had to make savings of £7bn to their adult social care budgets since 2010, though recent government injections of cash has offset this partially.<sup>46</sup>

## **Serbia**

In Serbia, Serbian DPOs received approximately three million euros (350 million Serbian dinars) annually from the national lottery to undertake projects tendered by the Department for Persons with Disabilities in the Ministry for Social Protection. Initially, there were many capacity building projects but now the Department maintains that DPOs have sufficient capacity and wishes to direct funds towards more innovative projects rather than fund further training. This could be problematic if capacity building is concentrated on those who were in the first wave and it might be better to continue to expand and spread to reach maximum numbers of DPOs. Other projects funded by the Department included the writing of an alternative report on CRPD implementation and the travel costs for two representatives of the National network of DPO's and their personal assistants to go and interact with the CRPD Committee in Geneva. In 2018, the Serbian Office for Human and Minority Rights funded the publication of an analysis of the implementation of the UN Committee's recommendations to

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<sup>45</sup> Carter, R (2019) Accelerating closure of user-led bodies, amid care cuts, creates 'perfect storm' for disabled people, Community Care  
<https://www.communitycare.co.uk/2019/04/29/accelerating-closure-user-led-bodies-amid-care-cuts-creates-perfect-storm-disabled-people/>

<sup>46</sup> ibid



Serbia (approximately €4,000).<sup>47</sup> In Serbia it is fairly easy to register as a non-governmental organization: three individuals who have legal capacity can do it, including children aged 14-18 years. There are no specific additional conditions for setting up a DPO in Serbia.

## **5.0. Ireland: Disability structures and participation**

In Ireland, the low numbers of representative DPOs are possibly the result of a combination of factors. These may include the strength of voluntary disability service providers and other disability charities that are not DPOs. Other reasons may include centralised government and fluctuating levels of funding to the third sector and civil society organisations. For example, in Ireland, after the financial crisis of 2008, funding to the voluntary and community sector had contracted by 35% at the end of 2013 – a contraction unmatched by any other European country.<sup>48</sup>

In the community and voluntary sector, there are four main types of disability organisations:

- DPOs and emerging DPO umbrella organisations.
- Voluntary disability service providers, of which many are charities, and which receive state funding. (There are also statutory disability service providers).
- Umbrella organisations that represent service provider organisations and other disability organisations.
- Advocacy organisations that are not DPOs.

There is currently no national funding mechanism for disability bodies or organisations to cover running costs where they are solely advocacy bodies (as opposed to offering services).

In 2020 several DPOs formed a DPO coalition. These DPOs are –

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<sup>47</sup> Personal communication from Damjan Tatic, lawyer, who has drafted Serbian laws on the rights of persons with disabilities, including the Law on the Prevention of Discrimination against Persons with Disabilities and who participated in drafting the CRPD Convention on the Rights of Persons with Disabilities. Damjan also served on the UN CRPD Committee.

<sup>48</sup> Harvey, B (2016) Local and Community Development in Ireland - An Overview in The Changing Landscape of Local and Community Development in Ireland: Policy and Practice Conference Proceedings held on the 21st October 2015, University College Cork Edited by: ISS21 Local and Community Development Working Group. Also, Harvey, B (2012) Changes in employment and services in the voluntary and community sector in Ireland, 2008-2012 <https://www.ictu.ie/download/pdf/downsizingcommunitysector.pdf>

- The National Platform of Self Advocates, a national DPO run by people with intellectual disabilities for persons with intellectual disabilities.
- The Independent Living Movement Ireland (ILMI), established as CIL in 1992, by and for persons with disabilities, is a national cross-impairment Disabled Person's Organisation (DPO). Working collectively, at a local, national and international level from the basis of the Social Model to ensure that all disabled person's voices are heard, the core values of Independence, Options, Rights and Empowerment are the foundation of the organisation. The ILMI recognises and promotes equality within their members, in terms of gender, sexuality, ethnicity, age, marital status, socio-economic status and impairment.
- The Irish Deaf Society, set up in 1981, promotes the Irish Sign Language (ISL), which is the language of the Deaf community, as their primary means of communication. It enables Deaf people to further their independence and improve participation in the community.
- AslAm, Ireland's National Autistic Charity, is a rapidly growing DPO. It started in 2014 as an online platform for people with Autism to access information and share experiences.
- Disabled Women of Ireland is an organisation dedicated to advocating for the rights of women with disabilities in Ireland. It advocates from an intersectional feminist approach.

Voluntary disability services are large industries in many parts of the world and, in Ireland, they also provide a lot of employment. Indeed, historically, they were often the biggest employer in some towns. The HSE funds voluntary disability service providers and many other disability organisations including, for example, Inclusion Ireland<sup>49</sup>, the National Federation of Voluntary Bodies<sup>50</sup> and the Disability Federation of Ireland.<sup>51</sup>

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<sup>49</sup> Inclusion Ireland was founded in 1961 as the 'National Association for the Mentally Handicapped of Ireland' and became known as NAMHI. Since December 2005 NAMHI has become Inclusion Ireland – the National Association for People with an Intellectual Disability. It provides information, advice and advocacy support.

<sup>50</sup> The National Federation of Voluntary Service Providers (FedVol) is the national umbrella organisation of voluntary/non-statutory agencies who provide direct services to people with intellectual disability and autism in Ireland through service arrangements with the HSE. Member Organisations account for more than 85% of direct service provision to people with an intellectual disability and autism in Ireland.

<sup>51</sup> Disability Federation of Ireland (DFI) is a support organisation for voluntary disability organisations who provide services to people with disabilities such as advocacy and representation networking, training, policy development and management development research.

While there is not a long history in Ireland of engagement with DPOs as laid out in the CRPD, Ireland has structured engagement with persons with disabilities on legislation, policies and practices that directly impact their lives. For example, the **Disability Stakeholders Group (DSG)** is a group of 24 individuals, appointed by the Minister of State for Disability, to monitor the implementation of the National Disability Inclusion Strategy (NDIS). The group includes persons with a lived experience of disability and members of disability organisations. Each member's tenure is as long as the Strategy they are monitoring - the current DSG is monitoring the implementation of NDIS 2017-2021. The current group includes representation of different types of disability and a geographical spread. DSG members are volunteers, and are not remunerated for their participation, apart from travel and subsistence costs.

The DSG members meet to review the implementation of the Strategy, participate in the national steering group and in meetings of departmental Disability Consultative Committees (DCCs). Nine government departments have DCCs that meet quarterly and review implementation of Strategy actions at department and agency. The DCC meetings can be attended by DSG representatives, NDA staff, department officials and other stakeholders, such as Departmental agencies or other disability stakeholders who are not part of the DSG, if invited by the Department in question. DSG members attend these meetings and request information from the Department regarding the progression of the actions for which it is responsible. The DSG representatives meet each other, also four times a year, to discuss the issues arising, in meetings chaired by an independent Chairperson. The NDA is not a member of the Group but provides secretariat support to the DSG and a small budget to cover costs of travel and subsistence for members. The DSG representatives report to the Chairperson on how each Department is progressing the NDIS actions.

The DSG members sit on the national steering group tasked with supporting the implementation of the Strategy and monitoring its progress. The National Disability Inclusion Strategy Steering Group is chaired by the Minister of State for Disability. Other members of that Steering Group include officials from most government departments and some key government agencies, and the NDA within its independent advisory role.<sup>52</sup> The DSG presents its views and

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<sup>52</sup> The National Disability Authority (NDA) was established in 2000 as an independent state body providing advice on disability policy and practice to the government and the public sector, and promoting Universal Design in Ireland. The NDA assists the Minister for Children, Equality, Disability, Integration and Youth in the co-ordination of disability policy. The NDA contributes to research and policy engaging bi-laterally and across Government Departments and agencies.

suggestions at these meeting through their Chairperson, but also includes input by individual members.

The DSG also provides input to the Comprehensive Employment Strategy (CES) Implementation Group. Similar to the NDIS, the CES is a cross-government strategy that brings together actions by different departments and state agencies in a concerted effort to address the barriers and challenges that impact on employment of persons with disabilities. As part of this programme, each relevant government department reports on its implementation of the CES to an implementation group, which meets quarterly and which is made up of officials from relevant departments and agencies, representatives from the NDA and nominated members of the DSG as well as other disability stakeholders nominated by the Chair. The CES Implementation Group is chaired by an independent Chairperson.

**The Disability Participation and Consultation Network** was launched in 2020 to provide a channel for involving persons with disabilities in developing policy and legislation, in line with the requirements of the UNCRPD. It is funded by the Department of Children, Equality, Disability, Integration and Youth. The Network is composed of

- an organising member, Inclusion Ireland
- four grant-funded Members (the DPO Coalition, As I Am (a DPO), Mental Health Reform and Disability Federation of Ireland)
- more than 70 individual voluntary members

The first meeting of the network was in January 2021 and the first duty of the group was to consult widely on Ireland's Initial State Report to the UNCRPD.

**Disability Advisory Committee** In December 2018, the Irish Human Rights and Equality Commission (IHREC), Ireland's independent monitoring mechanism under the UNCRPD, established a Disability Advisory Committee (DAC), comprising eleven people, a majority of whom are persons with disabilities representing a range of disability types. Appointments to the DAC are for a three-year term and follow an open competitive process.

The role of DAC is:

- To assist and advise the Commission on matters related to its function of keeping under review the adequacy and effectiveness of law and practice in the State relating to the protection of people with disabilities;
- To advise the Commission on the fulfilment of its independent monitoring role under the UN Convention on the Rights of Persons with Disabilities.

DAC met five times during 2019 and in its work has considered specific rights set out in the UN Convention, including:

- The right to political participation
- The right to independent living and participation in the community
- The right to participate in monitoring the Convention
- The right to participate in the implementation of the Convention; and
- The right to inclusive education

IHREC covers the costs of travel and subsistence for DAC members.

**Department of Children, Equality, Disability, Integration and Youth** In 2015, the Department of Children and Youth Affairs<sup>53</sup> launched the Government's first National Strategy on Children and Young People's Participation in Decision-Making 2015-2020, becoming the first country in Europe to do so. The goal of the strategy was to ensure that children and young people had a voice in their individual and collective everyday lives across the five national outcome areas set out in *Better Outcomes, Brighter Futures*. The strategy focused on the everyday lives of children and young people and the places and spaces in which they are entitled to have a voice in decisions that affect their lives, including in community, education, health and well-being, and legal settings. The strategy was primarily aimed at children and young people under the age of 18, but also embraced the voice of young people in the transition to adulthood.

In the strategy, HSE Disability Services committed to developing a framework document on how children's voices will inform the design, implementation and evaluation of disability services. This commitment was finalised in Year 3 of the strategy. By the end of 2019, 93% of actions had been completed. Children with disabilities participated in the strategy, including those with mental health difficulties and learning difficulties, as well as those with sensory impairments or intellectual disabilities, albeit in smaller numbers.

### **Other forms of participation**

Other forms of participation used to seek the views of persons with disabilities in respect of policy and practice include:

- **Public Participation Networks:** A Public Participation Network (PPN) is a network that allows local authorities to connect with community groups

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<sup>53</sup> In 2020 the Department of Children and Youth Affairs changed to the Department of Children, Equality, Disability, Integration and Youth.

around the country. A PPN is a resource for all local authorities who wish to benefit from community and voluntary expertise in their area. There are currently 31 PPNs around the country, many of whom have persons with disabilities as members. Several PPNs work together on the PPN Disability Network, which hosts seminars, makes submissions and carries out disability awareness training. For example, the Bray Area Partnership facilitates a forum for local disability groups, services and relevant statutory agencies, called the BAP Disability Network. The forum provides space for members to network, discuss common issues and identify local service gaps/policy issues to take joint action to promote the full and equal participation of persons with disabilities in the local community. In 2017, the Kerry PPN conducted a physical access audit in the four municipal districts of Kerry. This addressed a goal in the Kerry Local Economic & Community Plan 2016-2021 to create an environment where persons with disabilities could participate in their communities. The PPN ran workshops to gather information on access and then proposed actions and negotiated their incorporation into work plans with the Strategic Policy Committee.

- **Social Inclusion and Community Activation Programme (SICAP):** SICAP 2018 – 2022 provides funding to tackle poverty and social exclusion through local engagement and partnerships between disadvantaged individuals, community organisations and public sector agencies. The programme is managed at a local level by 33 Local Community Development Committees (LCDCs), with support from local authorities, and actions are delivered by Programme Implementers. An example of engagement was a SICAP-funded Development Officer who facilitated Access for All, a collaboration between a number of agencies and community groups, to highlight access issues in Galway City and to campaign for changes to improve access and facilities for people with disabilities.
- **Local Implementation Groups:** HSE Local Implementation Groups (LIGs) have been set up across the country to provide a local vehicle for the development of Primary Care Teams and Health and Social Care Networks in Community Healthcare Organisations (CHOs). The LIG's objective is to promote the vision of Primary Care Teams and Health and Social Care Networks in the CHO in line with national framework, policies, procedures and guidelines so as to enhance the delivery of primary care services to the local population and to work in partnership with general practice and other key stakeholders in realising this objective. Under the Progressing Children's Disability Services Programme, each CHO established a Local Implementation Group, which includes representatives of children's disability services, parents and other relevant stakeholders.

- **Strategic Policy Committees:** Strategic Policy Committee (SPCs) are local authority committees in city and county councils whose membership includes elected councillors, representatives of business, farming interests, environmental/conservation groups, trade unions and community and voluntary members. It is the task of the SPCs, as committees of the council, to advise and assist the council in the formulation, development and review of policy. The SPC system is intended to give councillors and relevant sectoral interests an opportunity for full involvement in the policy making process from the early stage. Several councils have a Social Development/ Community Inclusion SPC, which looks at disability matters through a local government lens.
- **The Mental Health Reference Group:** The HSE's Mental Health Division established a Reference Group to make recommendations on the structures and mechanism for Service User, Family Member and Carer Engagement, in the context of A Vision for Change. The membership comprised nine service users and four family and carer representatives. In line with their Terms of Reference, the group worked from August 2014 to July 2015, making recommendations for promoting widespread and regular engagement and consultation with service users, family members and carers at local and national level.<sup>54</sup> The HSE Mental Health Engagement Office engages with persons with mental health issues, family members, carers and friends. It is headed by a person with a history of mental illness. Each of the nine CHO Areas has an area lead person who works with service users, families, carers and other supporters. This person organises local forum meetings in which participants use their lived experience to work out how services might be improved. The CHO area lead person sits on the CHO management team and takes the issues raised and the suggestions made to the CHO team, which includes directors of psychiatry, nursing, psychology, occupational therapists and business managers. "Many items raised at meetings have been progressed quickly to improve services and supports. It is a co-productive, empowering, efficient and effective way of working with service users".<sup>55</sup> The HSE Mental Health Engagement Office engages in training and capacity building to support the engagement structures and roles. There is hope that the head of the

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<sup>54</sup> HSE Mental Health Division (2015) Partnership for Change: Report of the Mental Health Reference Group <https://www.healthpromotion.ie/hp-files/docs/HMT00982.pdf>

<sup>55</sup> Personal communication from CHO area lead

Mental Health Engagement Office will become an established member of the national mental health management team.<sup>56</sup>

## Conclusion

Participation of individual persons with disabilities and their representative organisations, DPOs, lie at the heart of the CRPD<sup>57</sup> to ensure that its principles and articles are actually implemented. In negotiating the challenges that exist in enabling DPOs and persons with disabilities to carry out their CRPD role, the spirit of the CRPD and its goal of full societal participation for persons with disabilities should guide all decisions with regards CRPD implementation. Whatever measures are taken should result in the translation of CRPD Principles and Articles into practice. Some alternative reports on CRPD implementation point out that their countries have not put into practice the formal positive changes they have made to laws and policies. Thus, ongoing openness and commitment to the CRPD spirit and the values enshrined in the UNCRPD Articles and Principles is crucial. The CRPD leaves States parties a large margin of freedom regarding how to implement an Article 33 structure that will ensure that DPOs and persons with disabilities participate effectively in making the CRPD a reality. It allows for the participation of NHRIs, Ombudsman offices, equality bodies, other human rights organisations, inspectorates, DPOs, trade unions, universities, research centres, and other organisations. Despite the potential for frameworks to form 'networks', most EU Member States have opted for solutions where NHRIs take the lead role. Article 33 does not explicitly mention NHRIs but they play an important role in promoting rights at the national level. In 75% of the EU Member States, including Ireland, that have assigned a mechanism to monitor implementation of Article 33, it is a single body, usually an NHRI.<sup>58</sup>

With regards civil society participation in the Article 33 framework, while the CRPD puts civil society involvement at the forefront, it does not specify that civil society organisations or their representatives must form part of the framework. Therefore, many consider that pluralism can be ensured through procedures that

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<sup>56</sup> Mental Health Engagement (working with service users, families and carers) <https://www.hse.ie/eng/services/list/4/mental-health-services/mentalhealthengagement/>

<sup>57</sup> General Comment No. 7 (2018), adopted at the 20<sup>th</sup> session of the CRPD Committee (27 Aug-21 Sept 2018), addresses the participation of persons with disabilities through their representative DPOs, in implementing and monitoring the CRPD.

<sup>58</sup> FRA (2016) Opinion of the European Union Agency for Fundamental Rights concerning requirements under Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities within the EU context [https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-opinion-03-2016-crpd.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-opinion-03-2016-crpd.pdf)



enable effective cooperation with diverse societal groups, for example, through advisory committees, networks, consultations or public forums.

While there is considerable latitude in how States implement the CRPD and, therefore, diversity in how States implement the CRPD, the following possibilities regarding the participation of DPOs and persons with disabilities are worthy of consideration:

- In addition to the main focal point (Article 33.1), one might consider appointing CRPD champions as focal points in each department and agency. These champions could coordinate CRPD awareness-raising, help outline what the Department is already doing to disability proof policies and plans and what they plan to do;<sup>59</sup> promote a study of how DPOs and/or persons with disabilities might input into the work of the department.
- Consider revisiting the key tasks of Article 33 (2) framework, which reflect its three dimensions: CRPD promotion, protection and monitoring.
- Consider the formal mechanisms for engaging persons with disabilities (Article 33.3), of all disability types, in all stages of the monitoring process to identify if they might be improved. This might include the focal point laying out how they will engage with DPOs and persons with disabilities and the Independent Monitoring Mechanism, often an NHRI, laying out how they will build close partnerships with DPOs as well as having, for example, a permanent consultation of DPOs. Government departments and agencies and other bodies could do likewise.

As part of Ireland's implementation of the CRPD, it will be important to engage local and community development entities as well as public services and government in implementing the CRPD. DPOs are important and it would be good to continue to include other civil society voices and to consider the provision of more capacity building for service providers to ensure they truly represent the voice of persons with disabilities.

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<sup>59</sup> The 2012 Disability Impact Assessment Guidelines is a key tool in this regard: How to Conduct a Disability Impact Assessment - Guidelines for Government Departments <https://www.justice.ie/en/JELR/20120305%20DIA%20Guidelines.pdf/Files/20120305%20DIA%20Guidelines.pdf>

## Appendix I: DPO Attributes

The New Zealand DPO Coalition developed a checklist of attributes an organisation should have to qualify it as a Disabled Persons' Organisation. It is important to note that these attributes were developed for the New Zealand context, and not all may be applicable in an Irish context but could be useful in developing a similar list here.

No.	DPO Attributes	Yes/No
1	The organisation has a legal existence i.e. must demonstrate it exists as a group of individuals with certain rules that bind them to a common purpose or goal	
2	The organisation has a national structure and focus. If the organisation has a regional focus, it demonstrates that there is no national organisation that speaks on behalf of its members	
3	The organisation upholds and promotes the philosophy that people with disabilities have the right to participate collectively in decisions that impact on our lives (Nothing about Us without Us)	
4	The organisation's primary goal, objectives and operations reflect and support the primary purpose of the Convention	
5	The organisation functions effectively and demonstrates it is putting into practice its constitutional requirements	
6	The organisation may focus on a single disability or it may be a multi-disability organisation. It is open to all disabled people who meet its membership criteria	
7	The organisation must be governed by a significant majority of disabled people who reflect its community of interest and meet its membership criteria	
8	Only disabled people who meet the organisation's membership criteria may elect and vote for its governing body	
9	A significant majority of the organisation's members are disabled and reflect its community of interest	

<b>No.</b>	<b>DPO Attributes</b>	<b>Yes/No</b>
10	The organisation demonstrates that it has a mandate or authority to speak on behalf of its members and this remains paramount over any other obligations including direct service provision	
11	The organisation responds to and is driven by the collective voice of its disabled members who reflect its community of interest	
12	The organisation demonstrates that it has strong links to its members throughout the country, or throughout the region for a regional organisation	
13	The organisation has a variety of ways to ensure its members are informed of key decisions at both a local and national level	

## Appendix 2: DPO involvement in implementing the UNCRPD

### 2014 FRA analysis

A 2014 analysis by the European Union Agency for Fundamental Rights (FRA) investigated whether EU Member States had mechanisms in place to involve DPOs in the development of disability laws and policies. This analysis showed that in nearly half (13) of EU Member States, the law provides for DPOs' engagement in developing laws and policies in different forms.

In Sweden, the constitution stipulates that the State must consult DPOs when developing disability law and policy. In Austria, Cyprus, Malta and Spain there is relevant disability-focused legislation.<sup>60</sup> In Germany, Hungary, Italy, Poland and Slovakia, general provisions require consultation of concerned parties and/or the public in law and policy-making processes and specify the duty to consult with DPOs.<sup>61</sup> In the remaining 15 EU Member States, the law does not require consultation and involvement of DPOs in developing laws and policies. In eleven of these Member States namely, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, Ireland, Latvia, Luxembourg and the UK, there are mechanisms for consultation with DPOs.<sup>62</sup>

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<sup>60</sup> For example, Article 9 of the Austrian Disabled Persons Act establishes a Federal Disability Board that includes seven representatives of “organised disabled persons and organised war invalids” and the Austrian government consults this body when drafting laws or policy-making. Cyprus defines the Confederation of Organisations of the Disabled, made up of nine DPOs, as the social partner of the state and the government consults with the confederation on decisions that directly or indirectly affect persons with disabilities.

<sup>61</sup> For example, federal ministries in Germany must consult concerned non-governmental organisations in law-making procedures or processes to develop political strategies. Similarly, Italian law establishes that non-governmental organisations (NGOs) active in the field of protection of the rights of persons with disabilities should be involved in the formulation and implementation of policies with regional consultative bodies and a national consultative assembly coordinated by the Ministry for Social Affairs  
<https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

<sup>62</sup> For example, the governments of Belgium, Bulgaria, the Czech Republic, Luxembourg and Latvia have consultative bodies of people with disabilities, which include representatives from DPOs. In the Czech Republic, DPOs are a part of the Government Board for People with Disabilities. Other governments have non-binding guidance regarding the involvement of civil society. For example, Estonia has the Good Engagement Code of Practice in Estonia establishes that government authorities have to include interest groups affected by a planned law during the drafting process. The government send affected interest groups the planned law so that they

Four member states, namely Greece, Lithuania, Netherlands and Romania, have neither legislation-establishing mechanisms nor systematic practices for consultation with DPOs in the development of their laws and policies. However, this does not mean that DPOs are not involved in practice.<sup>63</sup>

By November 2017, the CRPD Committee had reviewed initial implementation reports of 19 European countries: Austria; Belgium; Croatia; Cyprus; Czech Republic; Denmark; Germany; Hungary; Italy; Latvia; Lithuania; Luxembourg; Montenegro; Portugal; Serbia; Slovakia; Spain; Sweden and the UK.<sup>64</sup> Thus, there are evaluation reports by the CRPD Committee on these EU countries.

## **2016 IHREC analysis**

In 2016, IHREC analysed Article 33 Frameworks for Germany, the UK, Spain, Sweden, Malta and New Zealand<sup>65</sup> and one can see from Table I, which summarises the frameworks in the six countries studied by IHREC, that IHREC deems New Zealand compliant on all aspects of the framework as specified in Article 33.<sup>66</sup>

None of the states examined had an explicit method for individuals with disabilities to participate in the monitoring process apart from DPOs or umbrella groups. Most states with civil society participation focus on organisations, such as umbrella groups in the case of Spain and New Zealand or invited organisations in the case of Germany. While this may meet the current standards of the CRPD Committee, it does not meet the CRPD standard as understood by scholars.<sup>67</sup> Malta was the only state examined for the IHREC report that created a body composed of individuals with disabilities for its monitoring framework. One of

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comment on it <https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

<sup>63</sup> <https://fra.europa.eu/en/publication/2014/indicators-right-political-participation-people-disabilities/dpo-laws>

<sup>64</sup> <http://www.edf-feph.org/what-role-un-committee>

<sup>65</sup> IHREC (2016) 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of persons with disabilities'  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

<sup>66</sup> In 2016, the CRPD Committee had reviewed four of the six states that IHREC considers in its report. The report includes the views of the Committee and the civil society views on these four country frameworks. The remaining two countries have been analysed in the interim.

<sup>67</sup> DPOs disagree on certain aspects of the UNCRPD such as mainstreaming for all children with disabilities. Similarly, DPOs, scholars and others disagree on certain interpretations of the UNCRPD by the UN Committee. That is why the parallel reports and the dialogue with the UN Committee is helpful in progressing understanding of how best to implement the UNCRPD.

the dangers of using a group of DPOs as part of the monitoring framework is that segments of the disability community may not be involved. For example, in New Zealand, none of the six groups that initially composed the Convention Coalition represented people with mental health issues. This was later rectified.

**Table 1: Article 33 frameworks (2016)**<sup>68</sup>

State	Multibody Framework	Formal mechanism to consult with civil society	Civil society a permanent part of the framework	Created a DPO for the framework	'A' status NHRI in Framework
Germany		√			√
UK	√				√
Spain	√	√	√		√
Sweden	√				
Malta		√	√	√	
New Zealand	√	√	√	√	√

The report suggested that the creation of a body composed of individuals, similar to Malta, might avoid the problem of under-representation of groups.<sup>69</sup> At the same time it is challenging to expect an individual to represent an entire group (even if previously under-represented). This may be the case if they represent the whole range of person with disabilities. While the Committee looked for independent, properly resourced frameworks, civil society demands more. In Germany, Sweden, and the UK, where the monitoring framework lacked a permanent, formal role for civil society, civil society criticised the framework in its shadow reports, and requested a greater role in the process - even in Germany where civil society has a formal role in the coordination mechanism under Article 33.

Civil society in the UK noted that the monitoring framework was unable to carry out effective awareness raising, which limited its effectiveness.

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<sup>68</sup> ibid

<sup>69</sup> P.32, <sup>69</sup> IHREC (2016) 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of persons with disabilities'  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

Sweden used a government agency and an NHRI, not certified as fully independent, as its monitoring framework. The Committee criticised Sweden for not creating a monitoring framework that was independent of government.<sup>70</sup>

## Case studies

Below are a number of case studies that demonstrate the monitoring structures and DPO involvement in UNCRPD monitoring.

### **New Zealand: Article 33(2) compliant monitoring framework**

International comparisons have highlighted New Zealand's approach and its CRPD-compliant Article 33(2) monitoring framework. The UN Committee made no recommendations on New Zealand's implementation of Article 33 and Article 4.3 and in its concluding observations it commends New Zealand for establishing an independent monitoring mechanism in accord with the CRPD.

Its Independent Monitoring Mechanism (IMM) has a composition that is in line with the provisions of the Convention, in terms of its independence, involvement of DPOs and its mandate to promote, protect and monitor. No civil society or other groups who submitted reports criticised New Zealand's monitoring framework. "The fact that New Zealand was able to create an umbrella group that served the narrow purpose of ensuring civil society participation in the monitoring process - may be an encouraging example for Ireland, which lacks a pre-existing umbrella group in disability rights."<sup>71</sup> New Zealand's tripartite monitoring framework consists of the NHRI (the Human Rights Commission), Office of the Ombudsman and a newly created umbrella group of DPOs funded by the New Zealand government. This group, called the Convention Coalition Monitoring Group (CCMG), consists of representatives from national DPOs. New Zealand has a commitment at State level to comply with the obligations of the Convention and the creation of the CCMG, a DPO umbrella group for persons with disabilities-led monitoring of the CRPD demonstrates this commitment.<sup>72</sup>

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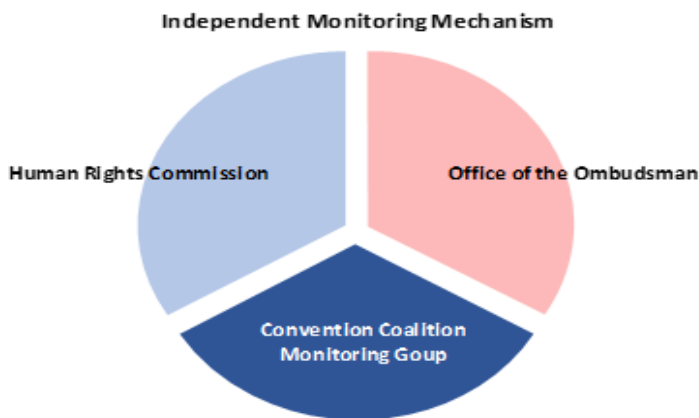
<sup>70</sup> IHREC (2016) 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of PERSONS WITH DISABILITIES'  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

<sup>71</sup> P.31, IHREC (2016) 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of PERSONS WITH DISABILITIES'  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

<sup>72</sup> Malatest International (2017) Review of disabled people led monitoring of the UNCRPD.  
<https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/report-on-the-review-of-disabled-people-led-monitoring/>

Figure 1 illustrates New Zealand's Independent Monitoring Mechanism.

**Figure 1: Structure of the Independent Monitoring Mechanism in NZ<sup>73</sup>**



The Human Rights Commissioner identifies disability issues and seeks solutions. The Ombudsman investigates complaints about state agencies regarding violations of the rights of persons with disabilities. The CCMG group governs the persons with disabilities-led component of the IMM. Figure 2 shows the channels for CCMG input into the IMM.

**Figure 2: Channels for CCMG input into the IMM.**



The CCMG provides a point for persons with disabilities to participate in the monitoring process. It coordinates an ethical mechanism for collecting the input of persons with disabilities to monitor disability rights. The approach comprises a

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<sup>73</sup> Malatest International (2017) Review of disabled people led monitoring of the UNCRPD. <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/report-on-the-review-of-disabled-people-led-monitoring/>

In 2016/2017, the Office for Disability Issues commissioned Malatest International to review disabled people-led monitoring in New Zealand. The review examined the effectiveness and efficiency of the 'disabled people-led monitoring of their rights' initiative and provided recommendations to inform future arrangements. Review published in May 2017.



qualitative research and monitoring programme that collects data directly from persons with disabilities.<sup>74</sup>

In comparison to Ireland, New Zealand has more and larger national DPOs, with more stable funding and more experience of contributing to human rights monitoring. For example, representatives from the majority of the DPOs in the New Zealand Coalition were involved in negotiations on the drafting of the CRPD, whereas in Ireland, only a few activists participated in negotiations.

The Office for Disability Issues in New Zealand commissioned a review of the monitoring mechanism. The 2017 review of the CCMG part of the IMM made some recommendations for further development. One recommendation was to clarify the functions of the CCMG and DPO Coalition and how they differ since the same DPOs participate in both groups. All DPOs are represented in the DPO Coalition by two people holding senior governance and management positions. All organisations that qualify as DPOs can participate in the CCMG. Some DPOs use the same representative for the DPO Coalition and for the CCMG while others use a different representative for each. Where DPOs are not represented by the same person in both groups, leadership can be distanced from the activity of the CCMG and be less aware of its operation.

Members who represent their DPO in both groups face an increased demand on their capacity, which they often have difficulty meeting. At times, the boundaries in the functions of each group have blurred. For example, monitoring issues have been carried from the CCMG to the DPO Coalition meetings for decisions and this has created confusion. Some government agencies have requested input from the CCMG on issues that are outside the scope of monitoring. Lack of clarity about the scope of the two groups is evident amongst monitoring stakeholders. The review suggested various options including:

- Absorbing the function of the CCMG into the DPO Coalition to provide clarity about governance, reduce workload and lead to a more effective governance structure. However, some stakeholders are concerned about the potential conflict of interest between the CCMG's monitoring function and the DPO Coalition's implementation role. Such conflicts might be managed by acknowledgement of their existence and transparency about how to manage conflicts
- Establish a new legal entity in place of the CCMG, which could be governed by the DPO Coalition and be the fund-holder for the monitoring. This would strengthen independence from government by taking the fund-holder back

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<sup>74</sup> Malatest International (2017) Review of disabled people led monitoring of the UNCRPD. <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/report-on-the-review-of-disabled-people-led-monitoring/>

from ODI, who has held the role temporarily and reluctantly. This approach would require the support of all DPOs

- Maintain the two groups but formalise the requirements of the role of DPO representatives

Other recommendations included: develop a monitoring framework with disability sector stakeholders that sets out monitoring priorities and appropriate monitoring measures to deliver the objectives; consider other perspectives that are currently under-represented; invest in developing the governance skills of CCMG members; define the scope of CCMG, distinguishing between operational matters and governance functions.

In a 2017 evaluation of structures, stakeholders provided feedback. This feedback included that DPOs are under resourced to meet demands placed on members, particularly those in leadership roles and those with particular skills. There is growing recognition of the need for input from persons with disabilities in steering and advisory groups across government to co-design services, research and evaluation. While meeting costs are covered, limited funding has been allocated to the development of expertise. The evaluation recommended that any changes in resource allocation would contribute to building the capacity of DPOs and their CCMG representatives. One stakeholder commented that it is challenging for some DPO representatives to participate as equals in meetings with senior public servants without sufficient investment in their training and development.

The review outlines specific opportunities for strengthening monitoring in the future. Feedback in the review focused on opportunities to strengthen the monitoring by undertaking certain tasks:<sup>75</sup>

- Revisiting and strengthening governance arrangements, for example, clarify the functions of CCMG and DPO Coalition and clarify how they differ. Use this knowledge to strengthen the leadership function of the CCMG. Invest further in developing the governance skills of CCMG members
- Further developing the structure of the monitoring through consultation and drawing on monitoring expertise to develop a monitoring framework to provide a foundation for the data collection, analysis and reporting
- Refining data collection methods to provide more opportunities for individuals and organisations of different types to participate. For example,

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<sup>75</sup> Malatest International (2017) Review of disabled people led monitoring of the UNCRPD. <https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/report-on-the-review-of-disabled-people-led-monitoring/>

consider including other perspectives which are currently underrepresented (for example family of disabled people, youth, some ethnic groups - Pacific people, Asians, new immigrants). People could be included as permanent members or seconded to the group

- Engaging with stakeholders throughout
- Building on the good work done on reporting in order to engage a wider audience with the monitoring findings.
- Developing a monitoring framework in partnership with disability sector stakeholders that sets out monitoring priorities and appropriate monitoring measures to deliver the objectives. Include or second research expertise in the group to support the development of a monitoring framework and CCMG technical decision- making

In terms of funding, New Zealand, the Human Rights Commission (the NHRI), and the Office of the Ombudsman, receive funding for CRPD responsibilities. The NZ Office for Disability Issues has two funding streams for DPOS. One funding stream is to enable DPOs to work and meet together as a coalition and provide collective advice to the government and to engage in governance of the Disability Action plan with government officials.

Since 2015/2016, about \$100,000 (€57,508) to \$120,000 (€69,014) has been budgeted annually for travel, accommodation, meeting fees and costs such as secretariat support and Sign Language interpreters. Prior to 2015/2016, individual DPOs invoiced individually for costs and funding for those years are reported as an estimate based on a search for expenditure in those years. The DPO Coalition established formal criteria that organisations are required to meet to qualify as DPOs. An organisation wishing to join the DPO Coalition, writes to them, provides a short description of the role of their organisation in representing persons with disabilities, outlines why they want to be recognised as a DPO and provide an assessment of their organisation against criteria laid down by the NZ DPO coalition. The DPO Coalition discuss and consider the application and may seek advice including from the ODI.

The second funding stream is available to the coalition to fund a contract for the monitoring of the implementation of the CRPD in New Zealand. The DPOs have additional funding streams through donations, membership fees, Government contracts, which cover the individual organisations' operational expenses.<sup>76</sup> The

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<sup>76</sup> Letter from the Ministry of Social Development, NZ, in response to an email request relating to Maori with disabilities. The questions included one on the funding provided to DPOs for their participation in the International Monitoring Mechanism for the UNCRPD each year for the past five years. Other questions included how the level of funding is decided and how does Office for Disability Issues (ODI) satisfy itself that the level of funding is appropriate?

actual spend varied each year depending on the actual number of meetings required. Table 2 shows the yearly spend.

**Table 2. Actual spend broken down by financial year<sup>77</sup>**

Financial year	DPO Coalition Meetings – actual spend	Disabled People Led Monitoring Contract – actual spend
2013/2014	\$2,245 = €1,291.45	\$275,000 = €158,152.30
2014/2015	\$43,614 = €25,088.34	\$336,499 = €193,526.61
2015/2016	\$183,190 = €105,372.99	\$169,706 = €97,600.97
2016/2017	\$105,641 = €60,765.92	\$71,023 = €40,846.60
2017/2018	\$138,181 = €79,467.79	\$164,097 = €94,369.08

There has been a longer history of participation in disability policy, etc. on the part of persons with disabilities and DPOs in New Zealand than in other countries. For example, DPOs and persons with disabilities from New Zealand were both involved in the process of drafting the CRPD. A review of the involvement of DPOs and disabled persons from New Zealand in the CRPD process concluded that their input was successful due to factors that included the following:<sup>78</sup>

- New Zealand’s officials were supportive of participatory processes and the manifesto of the Fifth New Zealand Labour Government (1999–2008) enhanced this position. This support for collaborative processes facilitated the input of DPOs and persons with disabilities.

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<https://www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/official-information-responses/2019/march/r-20190326-implementation-of-ministerial-priorities-on-disability-issues-for-maori-details-regarding-fundings-provided-to-dpos-dpo-representatives-for-the-past-five-years.pdf>

<sup>77</sup> Howard, A (2013) Placing Disability on the Policy Agenda: An Assessment of Participation in International Policy Processes by Disabled People’s, MA Thesis in Development and Emergency Practice, Oxford Brookes University  
[https://www.brookes.ac.uk/uploadedfiles/faculty\\_of\\_technology,\\_design\\_and\\_environment/school\\_of\\_architecture/site\\_assets/documents/amy-howard-ma-dissertation.pdf](https://www.brookes.ac.uk/uploadedfiles/faculty_of_technology,_design_and_environment/school_of_architecture/site_assets/documents/amy-howard-ma-dissertation.pdf)

<sup>78</sup> Howard, A (2013) Placing Disability on the Policy Agenda: An Assessment of Participation in International Policy Processes by Disabled People’s, MA Thesis in Development and Emergency Practice, Oxford Brookes University  
[https://www.brookes.ac.uk/uploadedfiles/faculty\\_of\\_technology,\\_design\\_and\\_environment/school\\_of\\_architecture/site\\_assets/documents/amy-howard-ma-dissertation.pdf](https://www.brookes.ac.uk/uploadedfiles/faculty_of_technology,_design_and_environment/school_of_architecture/site_assets/documents/amy-howard-ma-dissertation.pdf)

- The active political involvement of persons with disabilities

Key informants pointed out that as governments wield power they are the one who must facilitate collaboration. “Not all countries allowed their disabled people the same level of involvement as the New Zealand Government”.<sup>79</sup> Participatory processes were educational for government officials and for persons with disabilities. The processes helped government officials to understand the extent of discrimination faced by persons with disabilities. It was felt that government officials developed first-hand knowledge of the capabilities of persons with disabilities. The increased visibility of persons with disabilities provides role models for others and helps overcome negative perceptions of disablement.<sup>80</sup> Involving persons with disabilities in the development of the Convention reduced political game playing between nations. Inclusion of persons with disabilities made the issues real and ensured that the process moved forward. The ‘energy’ in the negotiations was improved and negotiations stayed on track time wise. Inclusion of persons with disabilities in the negotiation process resulted in a Convention that is more relevant and practical than other treaties. The participation of persons with disabilities ensured that “the Convention reflects a social model of disability, rather than a medical model”<sup>81</sup>

However, key informants also stated that the CRPD process was bureaucratic and complex and the final document technical. One key informant argued that the fact that the CRPD is difficult to interpret and complex weakens the position of the disability movement. This claim highlights an inherent contradiction. On the one hand, DPOs believe their participation made the documentation more relevant and that the convention reflected the voices of persons with disabilities. On the other hand, some considered that the documentation was too technical for DPOs to understand and apply. This devalues the CRPD for persons with disabilities as it prevents them from being able to hold their governments to account because they do not fully understand the principles and procedures in it. This could reflect the fact that the UN produced the final documentation after participation had occurred. The UN is a bureaucratic institution, which, by its own rules, means the CRPD process could never have achieved absolute user

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<sup>79</sup> Howard, A (2013) as above citing Moriarity L and Dew K (2011): The United Nations Convention on the Rights of persons with disabilities and participation in Aotearoa New Zealand, *Disability and Society*, 26(6): 683- 694.

<sup>80</sup> Howard, A (2013) as above citing Yeo R (2005). Disability, poverty and the new development agenda. Disability KaR Knowledge and Research, DFID, London.

<sup>81</sup> Howard, A (2013) as above citing Moriarity L and Dew K (2011): The United Nations Convention on the Rights of persons with disabilities and participation in Aotearoa New Zealand, *Disability and Society*, 26(6): 683- 694.

governance by DPOs. The process was top-down, instigated by the UN. The power in negotiation remained with it and the member states. In its dealings, while it heard the voices of persons with disabilities, the power balance remained in favour of the UN. In addition, the numbers of DPO participants and representations to the working groups within the CRPD process is uncertain, and their reflections on the process itself are absent in published research.<sup>82</sup>

### **Iceland: DPOs and legislation**

The Organization of Disabled in Iceland (ÖBÍ), is the national DPO with the number of member DPOs totaling 33. ÖBÍ's role is to represent persons with disabilities and to safeguard their interests, for example regarding legislation and the implementation of law and regulations. The organization furthermore provides consultation for disabled persons and their relatives. ÖBÍ is an active participant in cooperation with associations and organizations of persons with disabilities abroad. ÖBÍ is a member of the European Disability Forum (EDF).

This case study illustrates the impact of DPOs in the drafting of core disability legislation to align Icelandic law with the CRPD.<sup>83</sup> The initial stages of the drafting process started in 2014. DPOs were not meaningfully involved and there was a lack of political interest in issues affecting persons with disabilities. However, a general election resulted in a new Government who decided to review the draft legislation a second time. This last stage of the legislative process began in January 2018. A newly appointed committee asked for additional comments and suggestions from DPOs and from the Centre for Disability Studies at the University of Iceland. Identifying a window of opportunity, representatives and leaders of DPOs and the research community formed a joint working group. They formulated a strategy to strengthen their ability to influence the development of legislation and policy. The strategy included presenting a united front by focusing on issues where DPO positions aligned. Previously DPOs had focused on issues specific to the interests and needs of their membership, which had resulted in diverse and conflicting critical comments on draft legislation, etc. The new strategy was more successful. The united front of the working group, their in-depth knowledge of the CRPD, and their ability to state a right and an obligation by the State, as called for by the CRPD, was important. Being part of a

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<sup>82</sup> Howard, A (2013) Placing Disability on the Policy Agenda: An Assessment of Participation in International Policy Processes by Disabled People's, MA Thesis in Development and Emergency Practice, Oxford Brookes University  
[https://www.brookes.ac.uk/uploadedfiles/faculty\\_of\\_technology,\\_design\\_and\\_environment/school\\_of\\_architecture/site\\_assets/documents/amy-howard-ma-dissertation.pdf](https://www.brookes.ac.uk/uploadedfiles/faculty_of_technology,_design_and_environment/school_of_architecture/site_assets/documents/amy-howard-ma-dissertation.pdf)

<sup>83</sup> Löve, L., Traustadóttir, R., Rice, J (2019) Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing 'a Seat at the Table'  
<https://www.mdpi.com/2075-471X/8/2/111/pdf>

group created synergy, mutual support and shared enthusiasm for the work. It made it possible to divide the workload, which was useful as meetings happened at short notice and DPO representatives participated predominantly on a voluntary basis. Other factors perceived to have contributed to the success of the working group included strategies such as leaving a paper and electronic trail of suggestions, comments and memoranda to preclude claims of a lack of clarity concerning the DPOs' intent.<sup>84</sup>

Among changes to the draft that the members of the group attributed to their participation in the consultation process were changes to articles that instituted personal assistance as a legally mandated service form. The initial draft legislation allowed authorities to limit access to the right to personal assistance. The new working group pushed for personal assistance for everyone. The adopted law contains the right to personal assistance for disabled people, regardless of impairment or age. Members of the joint working group perceived that referring to the CRPD was effective in calling for changes to the draft legislation. Another change to draft legislation, achieved through DPO participation, was an addition to article 36 of the law, which states that membership of a consultative body to the Minister, must have a majority of disabled people. Leaders of DPOs consider that their emphasis on Article 4.3 of the CRPD also resulted in the Ministry consulting with them frequently. Members of the group emphasized their successful effort to change the name "Laws regarding services for disabled people with significant support needs" to "Laws regarding services for disabled people with long term support needs." Members of the joint working group took the lead in the translation of definitions, based on their understanding of the CRPD.<sup>85</sup>

However, research also shows that DPOs have had to dedicate a lot of time and energy to preventing roll backs of acquired rights.<sup>86</sup> An example cited was a directive issued by the Ministry of Welfare that expanded the number of apartments permissible within apartment complexes for disabled people. The DPO leader stated that his organization had opposed this action and had pointed out that increasing the number of units contradicted the CRPD. Another example was where proposals by representatives of DPOs on a proposed amendment to laws pertaining to facilitating equal access to actualize voting rights were disregarded. The proposed draft legislation did not include the suggested

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<sup>84</sup> *ibid*

<sup>85</sup> Löve, L., Traustadóttir, R., Rice, J (2019) Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing 'a Seat at the Table' <https://www.mdpi.com/2075-471X/8/2/111/pdf>

<sup>86</sup> Löve L., Traustadóttir, R., Rice, J (2018) Achieving Disability Equality: Empowering Disabled People to Take the Lead, *Social Inclusion*, 6 (1), 1–8

changes by DPOs while Icelandic disability law requires that due consideration be given in its execution to international obligations, particularly the CRPD, as stipulated by a 2010 amendment to the law. The limited ability of DPOs in Iceland to effect legislation and policy that relate to their lives in any stable way has led some DPOs to develop approaches that aim to empower persons with disabilities to become the leaders of the process of achieving full rights. The more recently formed activist DPOs have redefined issues that pertain to their needs and lives, based on their perceptions. They then present them in the public arena and this is allowing them to emerge more clearly as leaders and experts in their own affairs. However, the slowness of progress and the limited ability of DPOs in Iceland to effect legislation and policy that relate to their lives has led activist groups to develop approaches that aim to empower disabled people and assert them as the leaders of the process of achieving full rights. The more recently formed activist groups have redefined issues that pertain to their needs and lives, based on their perceptions and present them as such in the public arena. This allows them to emerge as leaders and experts in their own affairs.

Despite frustrations, other DPOs in Iceland continue to cultivate relationships with politicians, including parliamentarians, government ministers and elected officials at the local level. DPOs felt that they collaborated effectively with the authorities in a process that had led to the ratification of the CRPD – a process where they were also heavily involved behind the scenes. With their emphasis on collaboration, leaders of these DPOs reject the more confrontational approach employed by some activist DPOs. Nevertheless, many expressed support and even admiration for the work of these groups, particularly their effectiveness in generating public and media attention.<sup>87</sup>

DPOs participating in constitutional drafting has been a successful pathway to greater equality. DPOs in Egypt played an active role in shaping Egypt's new constitution in 2014. As a result the adopted draft includes a comprehensive article on the rights of persons with disabilities, while separate articles outline the rights of children with disabilities and establish the National Council of Disability Affairs. Similarly, DPOs were involved in constitutional reform processes in Uganda and South Africa both of which adopted strong protection for disability rights. Enshrining equal rights on the basis of the constitution has practical and normative value. Yet even without constitutional protection, DPOs and person with disabilities press for their rights through litigation and advocacy. In countries that have ratified the CRPD, DPOs and other civil society groups have used the

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<sup>87</sup> Löve L., Traustadóttir, R., Rice, J (2018) Achieving Disability Equality: Empowering Disabled People to Take the Lead, *Social Inclusion*, 6 (1), 1–8



CRPD to leverage improvements in accessibility in education, workplaces, public spaces, legislature, etc.<sup>88</sup>

### **Malta: consultation and dialogue with civil society**

Clarke (2017)<sup>89</sup> outlines the Maltese Government's approach to consultation and dialogue with civil society by promoting regular meetings with persons with disabilities, DPOs, other NGOs and stakeholders. Through these meetings, persons with disabilities highlight situations that hinder their rights and promote an understanding of the situation and needs of persons with disabilities. In addition, stakeholders are informed about Governmental projects and policies held by the Secretariat for persons with disabilities. Government action includes the following:

- The Parliamentary Secretariat holds weekly meetings with the National Commission for the Rights of Persons with a Disability (NCRPD). NCRPD is the Independent Monitoring Mechanism that audits their Government's implementation of the CRPD.
- The Parliamentary Secretary for Active Ageing and Persons with Disability holds regular meetings with persons with disabilities, their families, representatives and other stakeholders working in the disability sector. The Parliamentary Secretariat also holds weekly meeting with the Support Agency and other stakeholders. The Support Agency is a governmental body that offers community and residential services to persons with an intellectual disability.
- The Maltese Parliament passed legislation mandating the inclusion of at least one persons with disabilities on Governmental Boards. This bill enables persons with disabilities to be directly involved in strategic governmental decisions. It allows persons with disabilities to support their claims and articulate the need for decisions to respect their rights.
- The Committee for a Right Society composed of persons with disabilities, their relatives, representatives of persons with disabilities and other experts designed the first National Disability Policy for Malta, launched in December 2014.

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<sup>88</sup> Sprague, A., Raub, A., Heymann, J. (2020) *Advancing Equality: How constitutional rights can make a difference* University of California Press

<sup>89</sup> J Patrick Clarke (2017) *Removing Stereotypes by Increasing Participation of Persons with Disabilities*, Awareness Raising Panel, 27<sup>th</sup> March 2017 <https://rm.coe.int/168070193e>

## **Denmark**

The Disabled Peoples Organisation, DPOD, is the national umbrella organisation of persons with disabilities in Denmark. Established in 1934, DPOD is the umbrella DPO of 32 national democratic persons with disabilities organisations. DPOD is a member of the European Disability Forum (EDF), which is an umbrella organisation of DPO in Europe. The NHRI, which is the Danish Institute for Human Rights, collaborates with DPOD. In compliance with the Paris Principles, DPOD has representation on the NRHI board as part of the independent monitoring framework - five of the eighteen members are from DPOD. DPOD engages in the legislative process to implement the CRPD through informal and formal contacts and through meetings with civil servants, ministers and members of Parliament. They meet, for example, once or twice a year with the Ministry of Social Affairs, which is the focal point, to discuss disability issues. They write bilateral letters and use the mass media.<sup>90</sup> DPOD considered it an achievement to have an established structure, which is effective when it has qualified staff and sufficient resources. DPOD received approximately €120,000 from the government to cover costs of coordinating and drafting the alternative report of civil society for the initial review of Denmark for the CRPD Committee. This allocation of funding allowed DPOD to carry out the workload of drafting a comprehensive and systematic report on the Conventions implementation.<sup>91</sup> DPOD highlighted that in the ideal case, the State recognises and considers their opinions as well as providing them with education, financial support, information and transparent and accessible communication. Education should focus on democracy and techniques to improve representativeness of DPOs. DPOD defines necessary knowledge, sufficient resources, adequate complaint procedures and advisory services as prerequisites for the active and effective involvement of civil society.

## **Serbia**

In Serbia it is easy to register as a DPO or other non-governmental organization: three individuals who have legal capacity can do it, including children aged 14-18 years. There are no specific additional conditions for setting up a DPO in Serbia.

In Serbia there is one umbrella DPO, 15 national DPOs, 33 regional ones and 500 local DPOs. On an annual basis, Serbian DPOs receive ~3 million euros (350 million Serbian dinars) from the national lottery to undertake projects tendered

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<sup>90</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>91</sup> ibid

by the Department for Persons with Disabilities in the Ministry for Social Protection. One project was the writing of an alternative report on the implementation of CRPD and included funding the travel costs to Geneva for two representatives of the National network of DPO's and their personal assistants in order for them to interact with the CRPD Committee. In 2018, the Serbian Office for Human and Minority Rights funded (~ €4,000) the publication of an analysis of the implementation of the UN Committee's recommendations to Serbia. Two DPOs, the Centre for Independent Living – CIL Serbia, and the National Organisation of Persons with Disabilities Serbia (NOOIS) participated in the review process, including preparing and submitting the Alternative report to the UN Committee in June 2015 and its presentation to the Committee in September 2015.<sup>92</sup>

### **The United Kingdom (UK)**

In the UK, there was financial support to develop DPOs from 2005 to 2015 but not thereafter. In addition to ongoing welfare cuts, many DPOs and ULOs (user-led organisations) closed when Local Authorities withdrew funding. There is therefore a decline in DPOs and ULOs.<sup>93</sup> There is no statutory requirement on public bodies in England to engage with or fund DPOs. While the Social Services and Wellbeing Act 2014 in Wales requires local authorities to promote the involvement of persons using care, support and preventative services in their design and operation, there is no such requirement under the Care Act for English councils. However, the Equality Act 2010, and its public sector equality duty, which requires public bodies to have due regard to the need to reduce inequality, including between disabled and non-disabled people. This act has motivated public bodies to fund ULOs and DPOs through the duty's requirement for agencies to encourage participation by disabled people in cases where it is disproportionately low. The CRPD and the Equality Act together are clear that public bodies should fund DPOs. In 2018, the Office for Disability Issues announced it would create a regional stakeholder network to listen to the voices of persons with disabilities.<sup>94</sup>

The 2017 concluding observations of the CRPD Committee on the UK initial report on its implementation of the CRPD expressed concern about the lack of

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<sup>92</sup> Personal communication from Damjan Tatic, lawyer, who has drafted Serbian laws on the rights of persons with disabilities, including the Law on the Prevention of Discrimination against Persons with Disabilities and who participated in drafting the CRPD Convention on the Rights of Persons with Disabilities. Damjan also served on the UN CRPD Committee.

<sup>93</sup> <https://www.communitycare.co.uk/2019/04/29/accelerating-closure-user-led-bodies-amid-care-cuts-creates-perfect-storm-disabled-people/>

<sup>94</sup> *ibid*

support for DPOs and the absence of mechanisms to ensure their effective participation.<sup>95</sup> The Committee expressed concern over the following:

- Challenges facing organizations of persons with disabilities in accessing support and a lack of consultation and involvement of DPOs in CRPD implementation.
- Lack of mechanisms to ensure the effective participation of all organizations of persons with disabilities in decision-making processes concerning policies and legislation in all areas of the Convention such as the strategy entitled “Fulfilling Potential: making it happen”.

It recommended that the UK government

- Allocate financial resources to support DPOs including organizations that represent women and children with disabilities.
- Develop mechanisms to ensure the inclusive, strategic and active participation of DPOs, including organisations that represent women, children and intersex persons, in the planning and implementation of all legislation and measures that affect the lives of persons with disabilities.
- Establish mechanisms to secure the full participation of DPOs in the design and implementation of strategic policies aimed at implementing the CRPD across the State party, through objective, measurable, financed and monitored strategic action plans.

At the time of the 2017 report, the Chairman of the UN Committee criticised the UK’s welfare reform policies and care cuts for having neglected persons with a disability and creating “a human catastrophe”.<sup>96</sup>

A year later, in 2018, the UK Independent Mechanism (UKIM) update report to the UN Committee on the Rights of persons with disabilities (October 2018)<sup>97</sup> stated that the UK had taken limited steps to address the recommendations made by the CRPD Committee. UKIM expressed concern on the lack of a prompt response to the CRPD Committee’s recommendations and, in particular, the lack of a UK-wide strategy demonstrating how the UK will implement the CRPD Committee’s recommendations. A positive step acknowledged by UKIM is

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<sup>95</sup> Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland file:///H:/Downloads/G1728929.pdf

<sup>96</sup> <https://www.communitycare.co.uk/2019/04/29/accelerating-closure-user-led-bodies-amid-care-cuts-creates-perfect-storm-disabled-people/>

<sup>97</sup> <https://www.equalityhumanrights.com/sites/default/files/progress-on-disability-rights-in-the-uk-crpd-shadow-report-2018.pdf>

the announcement in May 2018 that the UK Government would establish an Inter-Ministerial Group on Disability and Society. However, they pointed out that the terms of reference for the inter-ministerial group do not refer to the CRPD or the Committee's recommendations and do not specifically provide for the participation of DPOs or persons with disabilities. It was not clear if devolved administrations are involved in the group. Without a clear plan for how the UK will address UN recommendations, steps taken are unlikely to address concerns raised by the CRPD Committee (p.7, UKIM, 2018). UKIM considers that there is ongoing reluctance from the UK to accept the conclusions of the CRPD Committee's report and highlights that persons with disabilities across the UK continue to face regression of their rights.<sup>98</sup>

DPOs in the UK united and prepared a three-hour presentation before a UN committee in Geneva on the different ways in which the UK government is breaching the CRPD.<sup>99</sup> The meeting took place four months after the CRPD found, following an inquiry, that the UK had committed "grave or systematic" breaches of the convention. This inquiry into the government's social security reforms is the first of its kind since the treaty came into force in 2008. The UK's chief executive of Disability Rights said that it was good to have the opportunity to put disabled people's experiences directly to the United Nations committee in Geneva:

- DPOs united and worked together to convey the top issues raised by disabled people (from all organisations). They presented a strong analysis of the biggest human rights challenges that the UK government need to address
- Those going to Geneva met or held tele-conferences to prepare together beforehand and worked together in Geneva as well. They unanimously agreed on the issues to present and collaborated on how to present them. One organisation led on a particular issue and others answered questions from the committee on that topic
- Diane Kingston, a former member of the CRPD committee helped DPOs to prepare for the three-hour session the International Disability Alliance and the European Disability Forum gave them advice in Geneva

In 2010, the Independent Mechanism in Northern Ireland<sup>100</sup> explored strengths and weaknesses of four established models for engaging with stakeholders:

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<sup>98</sup> ibid

<sup>99</sup> <https://www.disabilitynewsservice.com/dpos-join-forces-to-brief-un-on-how-uk-has-breached-disability-convention>

<sup>100</sup> The Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission jointly perform the role, under Article 33 (2) of the United Nations Convention on

advisory forum based on a 10-12 member panel; geographical roundtable focus groups; a network model and an annual public consultation. It concluded that states need a combination of models to fulfil all the requirements of Article 33 and to address the weaknesses of any single approach.<sup>101</sup> However, in 2016, the UN Committee again recommended that the UK and devolved governments improve participation of persons with disabilities as per Articles 4.3 and 33. In October 2018 a report on progress to the UN Committee stated that the “draft programme for government includes a commitment by the Northern Ireland Executive to involve disabled people in designing a structure for monitoring the implementation of the plan, including the setting up of a central regional disability forum involving disabled people. However, there is no evidence available in the public domain of progress towards realising this commitment. The Department for Communities has acknowledged that devolved departments are limited in what they can do without ministers in place to provide approval for new policies and additional resources.”<sup>102</sup>

### **The European Union**

In 2011, the European Union (EU) ratified the CRPD - the only international human rights' convention ratified by the EU as a regional integration organisation. Every EU member state has now ratified the CRPD. This implies a legally binding obligation for the EU institutions and Member States to implement their policies and programmes in line with the CRPD.

The EU's monitoring mechanism has five actors – or eight, if one considers the different committees of the European Parliament – jointly form ‘the EU Framework’: the European Parliament (three different committees), the European Ombudsman, the European Disability Forum (EDF), the European Commission and FRA. In its 2015 concluding observations on the EU's initial report, the committee commented on the European Commission's membership, suggesting

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the Rights of Persons with Disabilities (UNCPRD), of “Independent Mechanism” in Northern Ireland (IMNI) to promote, protect and monitor the implementation the Convention. Together with the Equality and Human Rights Commission (EHRC) and the Scottish Human Rights Commission (SHRC), we are designated as the United Kingdom Independent Mechanism (UKIM).

<sup>101</sup><http://www.equalityni.org/ECNI/media/ECNI/Publications/Corporate/IMNI%20meetings/2010/CRPD-2-5-Final-engagement-model-paper-23Apr10.pdf>

<sup>102</sup> <https://www.equalityhumanrights.com/sites/default/files/progress-on-disability-rights-in-the-uk-crpd-shadow-report-2018.pdf>

that the current multi-component structure (without the European Commission) does not raise major issues under the CRPD.<sup>103</sup>

At the EU level, the European Disability Forum (EDF) is a member of the monitoring framework along with the Fundamental Rights Agency, European Ombudsman and the European Parliament.<sup>104</sup>

In 2015, the UN committee reviewed the EU. It noted the lack of a systematic approach to including persons with disabilities in EU external policies and programmes. For the next review of the EU by the CRPD committee in 2021, the EU will report on how it has addressed the following issues in its international cooperation:<sup>105</sup>

- Adopt a harmonized policy on disability-inclusive development and establish a systematic approach to mainstream the rights of persons with disabilities in all international cooperation policies and programmes
- Appoint disability focal persons in related institutions
- Take the lead in the implementation of a disability-inclusive 2030 Agenda for Sustainable Development
- Put in place mechanisms to disaggregate data on disability in order to monitor the rights of persons with disabilities in EU development cooperation
- Interrupt EU funds used to perpetuate the segregation of persons with disabilities and re-allocate the funding to initiatives aimed at compliance with the CRPD

In June 2017, the EU adopted the New European Consensus on Development “Our world, our dignity, our future”. This Consensus aligns the European Commission's development policy with the 2030 Agenda for Sustainable Development and sets a common framework for development cooperation for the EU and its Member States. Persons with disabilities are explicitly included in the New Consensus with a commitment to implement and monitor the CRPD.

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<sup>103</sup> FRA (2016) Opinion of the European Union Agency for Fundamental Rights concerning requirements under Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities within the EU context [https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-opinion-03-2016-crpd.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-opinion-03-2016-crpd.pdf)

<sup>104</sup> [https://www.eud.eu/files/1814/7393/7249/Debrief\\_ERA\\_UNCRPD\\_seminar\\_-\\_for\\_website.pdf](https://www.eud.eu/files/1814/7393/7249/Debrief_ERA_UNCRPD_seminar_-_for_website.pdf)

<sup>105</sup> Axelsson, C (2019) Inclusion of persons with disabilities in European Union development cooperation mechanisms A preliminary study of calls for proposals in geographic and thematic instruments <https://bridgingthegap-project.eu/wp-content/uploads/Inclusion-of-persons-with-disabilities-in-European-Union-development-cooperation.pdf>

## Germany

The Federal Ministry for Labour and Social Affairs is the focal point within the German government and the German federal states appointed focal points as well. The Federal Ministry for Labour and Social Affairs liaises the 16 'sub'-focal points for all matters relating to the implementation of the UNCRPD.<sup>106</sup>

Germany established a single body, the German Institute for Human Rights, a NHRI, as its IMM in 2009. It carries out studies; meets with DPOs and persons with disabilities; inspects facilities for persons with disabilities and consults with experts. In this way, it generates a broader picture of the situation of persons with disabilities in Germany. It advises politicians, ministry and agency officials and the courts on issues relating to the CRPD. The CRPD IMM issues statements and makes recommendations regarding political, administrative and judicial decisions. When necessary, it calls for compliance with the CRPD. It organizes events addressing CRPD related issues and educates the public on the rights of persons with disabilities through press releases and outreach activities. The IMM makes information on CRPD issues available to interested persons on its website and in the library of the German Institute for Human Rights.<sup>107</sup> It hosts three consultations annually with civil society. Each consultation focuses on an issue of concern to the IMM. It invites over 60 groups, including DPOs, service providers, and groups representing family members of those with disabilities, to participate in the consultations.

Germany has a formal mechanism for civil society participation in its coordination mechanism within government, the Advisory Council on Inclusion. Most of the members of the Advisory Council are people with disabilities, while other members are representatives of other state bodies involved in implementation. The Council is responsible for liaising with society. It has four committees, made up of civil society groups involved in the implementation process, and composed of representatives from trade unions, churches, charities, research, and other organisations. The committees deal with: (1) health, long-term care, prevention, rehabilitation; (2) work and education; (3) freedom and protection rights, women, partnership, family and bioethics; (4) mobility, construction, housing, leisure, social participation, information and communication.

The UN Committee criticised Germany for not providing its monitoring mechanism with resources to fulfil its goals. Thus, a good choice of framework is not enough. It must have the resources to operate effectively. It recommended

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<sup>106</sup> <https://www.disability-europe.net/dotcom>

<sup>107</sup> German Institute for Human Rights on their CRPD Monitoring Mechanism <https://www.institut-fuer-menschenrechte.de/en/national-crpd-monitoring-mechanism/>



that Germany would strengthen the capacity of the monitoring mechanism and ensure that it had adequate resources. Civil society expressed dissatisfaction with the German monitoring arrangement<sup>108</sup> - a shadow report submitted by an alliance of German NGOs noted that the NGOs in the alliance were unhappy with their level of participation in CRPD implementation.

## **Sweden**

The Swedish Government submitted its first report to the UN Committee on the Rights of Persons with Disabilities (the Committee) in 2011. The Committee reviewed its report and gave its concluding observations in 2014. In October 2018, the Committee submitted its list of questions ahead of the combined second and third reports in 2019.

The Social Service Division of the Ministry of Health and Social Affairs is responsible for the co-ordination of disability policy in the Government and is the focal point for the CRPD.<sup>109</sup> There is no representation from the Swedish Disability Federation in the independent mechanism. Involvement of the Swedish Disability Federation happens on an ad hoc basis and DPOs do not receive stable funding to play a meaningful role in promoting and monitoring CRPD implementation.<sup>110</sup> The Ministry of Health and Social Affairs as focal point and Social Service Division responsible for Disability Policy Coordination has been criticised for not involving DPOs in its CRPD implementation activities.

The UN Committee considered the initial report of Sweden in March/April 2014 and published its concluding observations in April 2014.<sup>111</sup> It expressed concern over the following:

- Coordination responsibility lies with the Ministry of Health and Social Affairs instead of the ministry responsible for human rights and discrimination
- Sweden does not have an independent mechanism based on principles relating to the status of national institutions for the protection and promotion of human rights (Paris Principles) to monitor CRPD implementation.

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<sup>108</sup> IHREC (2016) 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of PERSONS WITH DISABILITIES'  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

<sup>109</sup> <https://www.disability-europe.net/dotcom>

<sup>110</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>111</sup> [docstore.ohchr.org](http://docstore.ohchr.org)

- There is a gap between policies followed by the State party and those followed by the municipalities with respect to CRPD implementation
- The system of indicators established to monitor CRPD implementation addresses areas that strictly relate to disability policy and does not cover all of the rights areas under the CRPD. There is a lack of indicators
- The reporting system is voluntary at the municipal level, even though the State Party had not made a reservation in this respect when ratifying the CRPD

To establish an independent monitoring mechanism, the Swedish government appointed an inquiry in 2018 to investigate and submit proposals on establishing a national human rights institution (NHRI). It is currently studying the proposals received at the end of 2018. In addition, the government is developing various mechanisms to ensure that DPOs and persons with disabilities participate in the CRPD monitoring mechanism. It has a Disability Delegation, which is a forum for consultation and dialogue. Government representatives meet the forum four times a year and discuss monitoring the CRPD and the policies under development. The Chair of the Disability Delegation is the minister who has responsibility for coordinating disability policy. The government obtains opinions from DPOs on specific issues through a variety of discussion forums. In 2018, it had a discussion forum regarding the CRPD Committee's recommendations. In this forum, the government provided information on its work on the recommendations and on its bill on the national goal and direction of disability policy to obtain the views of the DPOs. The government sought the help of the Disability Delegation in preparing its responses to the UN Committee and held two special meetings in 2019 with representatives from civil society organisations including DPOs. DPOs or persons with disabilities are also included as experts in governmental inquiries.<sup>112</sup>

With regards developing indicators and helping the municipalities to implement the CRPD, the Swedish Agency for Participation with a remit to work towards participation for all, actively involves DPOs and is working with the municipalities including what indicators to use, etc. It monitors public sector actors' work to implement disability policy at national, regional and local levels. Between 2014 and 2016, it monitored the efforts of municipalities and regional public transport authorities to ensure accessibility and participation, using various indicators (labour market, education, culture, sport, physical accessibility and transport).

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<sup>112</sup> The Ministry of Health and Social Affairs (October 2019) Responses to questions from the UN Committee on the Rights of Persons with Disabilities  
<https://www.regeringen.se/4aa39a/globalassets/regeringen/dokument/socialdepartementet/funktionshinder/crpd---submission-of-the-combined-second-and-third-reports-of-sweden.pdf>

This monitoring was difficult so in 2015, the Agency worked with other agencies to develop its monitoring. It developed a survey in consultation with disability organisations, the Swedish Association of Local Authorities and Regions and a selection of municipalities, county councils and government agencies. Since 2017, it has carried out a survey of municipalities, county councils and government agencies and is developing a digital tool to replace the survey mailings. The results of its monitoring shows that longer term, systematic work at management level is a success factor for disability policy to have an impact in practice.<sup>113</sup> Since 2018, the Swedish Agency for Participation has an agreement with the disability movement, which includes a disability council that meets three times a year and deals with strategic and disability issues at management level. The Agency also involves the disability movement and civil society in other ways. The Agency has developed a consultation model for strategic and effective cooperation with the disability movement and civil society. The disability movement has representation on the Agency's knowledge council and the Agency plans to draw up support materials on active involvement for the municipalities.<sup>114</sup>

## **Spain**

The focal point in Spain is the Ministry of Foreign Affairs and Cooperation with the Ministry of Health, Social Services and Equality, via the Directorate General for Disability Support Policies. The government created the Commission on Integral Policies on Disabilities, within the Congress of Deputies, with this purpose.<sup>115</sup> Its coordination mechanism is the National Disability Council, a consultative body composed of members of the various ministries in government and 16 representatives from DPOs.

CERMI is the umbrella organisation representing 6,000 DPOs in Spain; it raises awareness and protects the rights of disabled people in Spain, drafts proposals to improve the legislation of the government, and occasionally represents disabled people in court. Implementation of Article 33 in Spain shows a potential way the Committee can have a direct impact on domestic law.

Initially, Spain designated the Spanish Committee of Representatives of People with Disabilities (CERMI) as the independent mechanism under Article 33(2), assuming it would fulfil the requirements under Article 33(3) as well. The CRPD Committee asked Spain to consider and report on whether CERMI is compliant

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<sup>113</sup> The Ministry of Health and Social Affairs (October 2019) Responses to questions from the UN Committee on the Rights of Persons with Disabilities  
<https://www.regeringen.se/4aa39a/globalassets/regeringen/dokument/socialdepartementet/funktionshinder/crpd---submission-of-the-combined-second-and-third-reports-of-sweden.pdf>

<sup>114</sup> *ibid*

<sup>115</sup> <https://www.disability-europe.net/dotcom>

with the Paris Principles. As an umbrella DPO, CERMI is not compliant with the Principles, so Spain included the Ombudsman, an NHRI, in the monitoring framework by adapting the Royal Decree before the Committee issued the Concluding Observations. This is an example of a State's willingness to comply with obligations in cases that require only a formal act to achieve that. The formal involvement of the independent element does not guarantee that the framework will succeed in practice, but it does establish a framework with the potential to become a solid base for independent and inclusive monitoring. The Committee commended Spain in its Concluding Observations for realising the need to establish a CRPD-compliant structure.<sup>116</sup>

Thus, Spain has two independent mechanisms to promote, protect and monitor the implementation of the Convention: the Spanish Ombudsman, and CERMI, the Spanish Committee of Representatives of People with Disabilities. To support CERMI's work as a monitoring body, CERMI created a 26-member committee including human rights bodies; political and parliamentary representatives; representatives of relevant national ministries; representatives of regional and local bodies; and representatives of academia, among others. The FRA view is that such advisory committees are an appropriate means to guarantee pluralism.<sup>117</sup> According to FRA, Spain's Article 33 (2) framework is the only one that the CRPD Committee has judged is in full compliance with the CRPD. The CRPD Committee commended Spain 'for establishing independent monitoring mechanisms in full compliance with Article 33(2) of the Convention' and there were no complaints from civil society about the monitoring mechanism. IHREC also highlights that "Spain presents an example of how Article 33 bodies, including the focal point, coordination mechanism and monitoring framework, can actively involve civil society."<sup>118</sup> IHREC wrote that "For states like Spain, with an existing, well-regarded and cross-disability NGO, this kind of framework could be an attractive option. For Ireland, which lacks a single umbrella group for all DPOs and NGOs working on disability issues, and where individuals do much of the work of disability rights activism, the idea of a permanent civil society body in the

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<sup>116</sup> *ibid*

<sup>117</sup> [https://fra.europa.eu/sites/default/files/fra\\_uploads/fra-opinion-03-2016-crpd.pdf](https://fra.europa.eu/sites/default/files/fra_uploads/fra-opinion-03-2016-crpd.pdf)

<sup>118</sup> P. 25, IHREC (2016) 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of persons with disabilities'  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

monitoring framework would probably require the development of a new organisation”.<sup>119</sup>

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<sup>119</sup> P. 25, IHREC (2016) ‘Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of persons with disabilities’  
<https://www.ihrec.ie/app/uploads/2016/09/Establishing-a-Monitoring-Framework-CRPD-WEB.pdf>

## **Appendix 3: List of the Articles of the CRPD**

Preamble

Article 1 – Purpose.

Article 2 – Definitions.

Article 3 – General principles.

Article 4 – General obligations.

Article 5 – Equality and non-discrimination.

Article 6 – Women with disabilities.

Article 7 – Children with disabilities.

Article 8 – Awareness-raising.

Article 9 – Accessibility.

Article 10 – Right to life.

Article 11 – Situations of risk and humanitarian emergencies.

Article 12 – Equal recognition before the law.

Article 13 – Access to justice.

Article 14 – Liberty and security of person.

Article 15 – Freedom of torture or cruel, inhuman or degrading treatment or punishment.

Article 16 – Freedom from exploitation, violence and abuse.

Article 17 – Protecting the integrity of the person.

Article 18 – Liberty of movement and nationality.

Article 19 – Living independently and being included in the community.

Article 20 – Personal mobility.

Article 21 – Freedom of expression and opinion, and access to information.

Article 22 – Respect for privacy.

Article 23 – Respect for home and the family.

Article 24 – Education.

Article 25 – Health.

Article 26 – Habilitation and rehabilitation.

Article 27 – Work and employment.

Article 28 – Adequate standard of living and social protection.

Article 29 – Participation in political and public life.

Article 30 – Participation in cultural life, recreation, leisure and sport.

Article 31 – Statistics and data collection.

Article 32 – International cooperation.

Article 33 – National implementation and monitoring.

Article 34 – Committee on the Rights of Persons with Disabilities.

Article 35 – Reports by States Parties.

Article 36 – Consideration of reports.

Article 37 – Cooperation between States Parties and the Committee.

Article 38 – Relationship of the Committee with other bodies.

Article 39 – Report of the Committee.  
Article 40 – Conference of States Parties.  
Article 41 – Depositary.  
Article 42 – Signature.  
Article 43 – Consent to be bound.  
Article 44 – Regional integration organizations.  
Article 45 – Entry into force.  
Article 46 – Reservations.  
Article 47 – Amendments.  
Article 48 – Denunciation.  
Article 49 – Accessible format.  
Article 50 – Authentic texts.

## **Appendix 4: The CRPD, DPOs and full societal participation**

### **DPOs and participation in the CRPD, a human rights principle**

Participation of persons with disabilities, whether through DPOs or individuals, in policy- and decision-making, and in monitoring CRPD implementation, is at the heart of the CRPD.<sup>120</sup> The CRPD recognises persons with disabilities as primary stakeholders, active participants and equal partners in State action on disability issues. To ensure their rights and full societal inclusion, the CRPD shines a spotlight on participatory processes, which it considers are central to promoting and attaining sustainable social change: DPOs and persons with disabilities are to participate in policy- and decision-making and monitoring CRPD implementation.

Article 4.3 specifies that States Parties consult with and involve persons with disabilities through their DPOs. Article 33 clarifies that the oversight and independent monitoring of the CRPD's implementation involve the direct participation of DPOs and persons with disabilities.<sup>121</sup> Thus, States who ratify the CRPD set out on the journey of planning systematic engagement with DPOs. This involves a process of change management that includes changing attitudes, making conscious decisions re how to implement the CRPD and taking specific actions to treat persons with disabilities as equal partners in policy and monitoring processes. Changing attitudes involves governments and civil society recognising the value and benefits of persons with disabilities participating as experts by lived experience in the issues that affect them.

The concept of full and effective participation means that society, in its public and private dimensions, enables everyone to take part fully in their communities. This means that society and relevant actors must value and recognise persons with disabilities as equal participants, for example, in processes related to decisions that affect their lives or in the freedom to run for public office. Participation goes beyond consultation to meaningful engagement in decision-making processes and

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<sup>120</sup> General Comment No. 7 (2018) adopted at the 20<sup>th</sup> session of the CRPD Committee (held between 27 August and 21 Sept 2018) addresses the participation of PERSONS WITH DISABILITIES, including children with disabilities, through their representative organisations, in the implementation and monitoring the CRPD.

<sup>121</sup> Page v, Emily Logan, Chief Commissioner, Irish Human Rights and Equality Commission, in the foreword to the 2016 Report, 'Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of PERSONS WITH DISABILITIES' produced by the Centre for Disability Law and Policy School of Law & Institute for Life-course and Society, NUI Galway



activities and the possibility to voice their opinions and complain when denied participation.<sup>122</sup>

As a human rights principle, participation requires implementing the related principles of inclusion, empowerment, sustainability and self-advocacy. Inclusion requires an accessible, barrier-free physical and social environment that promotes the full participation of persons with disabilities in their communities. Inclusion requires that society becomes accessible to persons with all forms of impairment irrespective of their cause or nature. It ensures that persons with disabilities can participate in community life as equal members. It places them and their issues in the mainstream of activities, rather than as an after-thought or add-on. To attain inclusion, attitudes often need to be changed as they influence behaviour and social life, ranging from interpersonal relationships and community associations to political, economic and legal structures.

Empowerment means that persons with disabilities and their families have the opportunity to take leadership roles, make decisions and control how they use resources. Sustainable activities require adequate technical, financial and organisational structures.

Self-advocacy means consistent and central involvement of persons with disabilities in defining their goals. It is a collective notion that involves self-determination, mobilization, organisation, representation, creation of space for interaction and demands. It means having the space to communicate verbally or non-verbally about oneself and one's likes, dislikes, wants and needs, etc. All people, even those with severe intellectual disabilities, can communicate and express themselves. Self-advocacy is an important feature of the disability movement and of DPOs and are central to producing knowledge about the rights of persons with disabilities. However, differences and tensions between groups of persons with disabilities can exist, and persons with intellectual disability can often be a group that finds it more challenging to navigate this landscape. A study in the UK and Hungary found that self-advocacy is a useful tool in this regard, and one could explore this in the context of the disability movement<sup>123</sup> where persons with intellectual disability and autism may not have a strong voice. While the CRPD requires persons with disabilities and their DPOs to play a prominent role in the monitoring and implementation of the Convention, professionals or

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[https://www.ohchr.org/Documents/Publications/CRPD\\_TrainingGuide\\_PTSl9\\_EN%20Accessible.pdf](https://www.ohchr.org/Documents/Publications/CRPD_TrainingGuide_PTSl9_EN%20Accessible.pdf)

<sup>123</sup> Petri, G., Beadle-Brown, J., Bradshaw, J (2017) More honoured in the Breach than in the Observance, *Laws*, 6, 26 <https://www.mdpi.com>

parents often represent persons with intellectual disability and autism. The study found that DPOs, human rights groups or state bodies develop implementation reports on the CRPD but persons with intellectual disability and many people with autism almost never have a prominent role in drafting such reports, let alone participate in drafting them. Self-advocacy for persons with intellectual disability and autism is an important opportunity for them to have their voice and develop the skills to do so.

The same study showed that a significant part of the advocacy movement working for people with intellectual disability and autism had little knowledge about the CRPD and human rights. Self-advocates and non-disabled advocates in both countries agreed that involvement of self-advocates in organisations, including in major DPOs is on the level of informing and placation. The marginalisation of self-advocates with intellectual disability is rooted in many factors and the low levels of meaningful participation runs the risk that the disability movement, even when using the ‘human rights model’, pursues advocacy targets that are not determined by self-advocates themselves. In the main, existing power-relations within the movement often still leaves others in control. Some participants saw examples of good practices but few of them saw real improvement in meaningful participation of self-advocates in the movement. Self-advocates with knowledge were likely to be in national umbrella DPOs that work with international organisations. The disability rights movement needs to address the ongoing limited participation of self-advocates in the movement and start planning and implementing progressive changes. DPOs can involve people with intellectual disabilities or autistic people within their human rights advocacy.”

Many states find the participation requirement in consulting and involving persons with disabilities in disability issues and in monitoring and implementing the CRPD challenging. Implementing the economic, social and cultural provisions of the CRPD, such as accessibility, reasonable accommodation and right to cultural life, requires financial investment. In contrast, while involving DPOs and individual persons with disabilities in decision-making requires some financial support, it primarily needs a change of attitude and decisions to oppose discrimination and set up practical mechanisms that include DPOs and persons with disabilities as outlined in the CRPD. <sup>124</sup><sup>125</sup>

The CRPD assumes that States who have ratified the CRPD will pro-actively seek their help in implementing and monitoring the CRPD and fund their support

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<sup>124</sup> Petri, G., Beadle-Brown, J., Bradshaw, J (2017) More honoured in the Breach than in the Observance, *Laws*, 6, 26 <https://www.mdpi.com>

<sup>125</sup> *ibid*

costs if there are not already existing funding mechanisms in place. In addition to attitude change, implementing the spirit of the CRPD so that the quality of life of persons with disabilities improves requires commitment, collaboration and creativity.<sup>126</sup> It also requires increasing awareness of discrimination as many persons with disabilities experience disadvantage and discrimination.<sup>127</sup> There are countries that do not give self-advocacy DPOs, comprised of persons with intellectual disability, legal status because their laws and regulations deny the legal capacity of persons with intellectual disabilities.<sup>128</sup> DPOs advocating for the rights of persons with intellectual disabilities can support their participation in disability issues including monitoring and implementation of the CRPD and increase awareness of their discrimination. Umbrella DPOs, in the spirit of the CRPD, can accept all DPOs as members to ensure that their organisations are representative of persons with disability. Including self-advocates with intellectual disabilities, as full members of DPOs, requires adapting formats and processes to meet their needs and providing the training that is necessary for them in order to participate effectively.<sup>129</sup> Capacity building within DPOs including an understanding of policy processes, technical, administrative and communication skills and access to information and tools concerning their rights, legislation and policymaking, is essential so that they can work strategically to support CRPD implementation.

Even when DPOs and persons with disabilities are formally involved in policy processes, they may not influence the outcomes in any significant way. Capacity building and empowerment of DPOs are essential to enable persons with disabilities to have a real voice and address dissatisfaction with ongoing practices. She notes that in her research strong disability movements had evolved as grass-roots movements initiated by persons with disabilities themselves.

The International Disability Alliance (IDA) supports DPOs worldwide to take part in UN and international human rights processes, and to use international

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<sup>126</sup> Making disability rights real in New Zealand. Annual report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities 2011 – 2012  
[file:///H:/Downloads/New%20Zealand\\_Special%20Report%20on%20CRPD%20Monitoring\\_2011\\_2012\\_EN%20\(1\).pdf](file:///H:/Downloads/New%20Zealand_Special%20Report%20on%20CRPD%20Monitoring_2011_2012_EN%20(1).pdf)

<sup>127</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>128</sup> General Comment No. 7 (2018) can be accessed with the other General Comments issued by the Committee at <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>

<sup>129</sup> Petri, G., Beadle-Brown, J., Bradshaw, J (2017) More honoured in the Breach than in the Observance, *Laws*, 6, 26 <https://www.mdpi.com>

accountability mechanisms. It advocates for an inclusive global environment, laying down a roadmap for the full implementation of the CRPD, including the effective participation of DPOs and persons with disabilities. It works toward ensuring that the 2030 Agenda and the Sustainable Development Goals are inclusive and in line with the CRPD. The IDA is an alliance of eight global and six regional DPOs. It defines a global organisation as a legally established one with a global mandate and comprising member organizations from at least 50 individual countries and with members in at least 3 continents.<sup>130</sup> With regards attaining effective participation, IDA suggests that DPOs may need to undertake the following actions:<sup>131</sup>

- Request from States that DPOs are fully and meaningfully involved in relevant national strategies and decision-making processes
- Request DPO membership of relevant Committees and monitoring structures
- Ensure that States target full accessibility, as this is a central CRPD objective
- Ensure that all legislation, regulations, policies, budgets and practices are consistent with the CRPD and that legislation protects from discrimination based on disability
- Raise awareness on the rights of persons with disabilities and the CRPD to different target groups including persons with disabilities and their families. Representative DPOs should be actively involved in awareness raising
- Increase the capacity of DPOs in terms of CRPD implementation and monitoring such as alternative reports, policy analysis, legal work, etc. To be effective, DPOs must acquire a knowledge of the implications of the CRPD; an understanding of how to use regional and international monitoring processes to support their advocacy work; skills to produce robust parallel reports to the UN Committee and other UN human rights treaty bodies, etc
- Strengthen co-operation among DPOs in order to maximize their impact. Build bridges and alliances with human rights NGOs (women, children, against torture, etc.) as this allows DPOs to learn from the experience of other

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<sup>130</sup> The majority of IDA member organizations shall be DPOs, that is, composed and governed by persons with disabilities or, in the case of persons with intellectual disability, composed and governed by persons with intellectual disability and family members. The global organisation shall have a majority of persons with disabilities in the governing bodies of the organization, or in the case of persons with intellectual disability, persons with intellectual disability and family members are in the majority of the governing bodies of the organization. Its members elect leaders democratically. The IDA considers that a regional organisation is one that is a legally established regional organization with national members in at least two-thirds of the countries of the region and open to the membership of all constituencies of persons with disabilities.

<sup>131</sup> <http://www.internationaldisabilityalliance.org/resources/steps-after-ratification>

NGOs and contribute to an increased focus on the rights of persons with disabilities by these other organizations

- Monitor mainstream developments and proactively request their participation in relevant mainstream initiatives as well as disability specific initiatives
- With regards the focal point, DPOs can request that the focal point is located at the highest possible level to ensure that it influences relevant government departments. DPOs can advise that departments create disability focal points that coordinate the work in government department<sup>132</sup> and involve umbrella DPOs in their meetings. With regards coordination and independent monitoring mechanisms in decentralized countries, coordination structures between the central level and the different regions are important. DPOs can request from their States that an independent mechanism is established (or that they allocate the task to an existing one), which meets Paris Principles
- DPOs need to plan how they will improve their capacity to analyze policy formulation and implementation, including understanding statistical data collection and consolidation, budgeting processes, policy review mechanisms, etc. They need to understand the major policy tools of their country. For instance in many low-income countries, support to persons with disabilities is often channeled through programs funded by international cooperation which often are extra-legal and extra-budgetary although presented as governmental action. In addition, DPOs require skills and knowledge on how to use the national legal system and, in particular, the use of strategic litigation
- The revision and aligning of legislation to the CRPD includes disability-specific and mainstream legislation relevant for persons with disabilities, including education, employment and electoral laws. Experience shows that the priorities of legal harmonization vary between more and less developed countries and are dependent on awareness of policy makers and DPOs. Some advanced provisions of the CRPD require modifications to the Civil Code or equivalent legislation and imply the need to modify the Constitution

Birtha (2016) teases out what **effective** participation entails and, in her research, respondents highlighted certain factors as prerequisites of effective involvement.

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<sup>132</sup> For states that wish to appoint multiple focal points, the UN Office of the High Commissioner for Human Rights (OHCHR) recommends placing focal points in each ministry, to address the fact that full implementation of the Convention requires action by most ministries or government departments - in 2009 Thematic study by the Office of the United Nations High Commissioner for Human Rights on the structure and role of national mechanisms for the implementation and monitoring of the Convention on the Rights of Persons with Disabilities <https://www2.ohchr.org/english/bodies/hrcouncil/docs/13session/A-HRC-13-29.pdf>

<sup>133</sup> Interestingly, there were many overlapping points regarding the factors that lead to effective participation, regardless of the respondent's country of origin or satisfaction with the current level of involvement. These included commitment of decision-makers to implementing the CRPD, collaboration among DPOs, capacity building, involvement of DPOs and persons with disabilities from the early stages of policy processes, providing decision-makers with evidence-based information and an active working relationship between the government, NHRI and civil society.

## **The CRPD and the reporting cycle**

The UN Convention<sup>134</sup> on the Rights of Persons with Disabilities (UNCRPD and abbreviated to CRPD and the Convention), an international human rights treaty adopted by the UN in 2006, recognises, reaffirms and guarantees the rights set out in the Universal Declaration of Human Rights. It confirms that persons with disabilities are equal to other persons as their rights under the CRPD are the same as under other human rights instruments. It protects the rights and dignity of persons with disabilities and aims to ensure that states put in place the mechanisms that will uphold their rights. It seeks to empower persons with disabilities, individually and through Disabled Person's Organisations (DPOs),<sup>135</sup> to participate in attaining societal participation through implementing the CRPD. The CRPD specifies that, in addition to DPOs, umbrella DPOS or other bodies set up by a state, persons with disabilities should be able to participate in the monitoring process if they wish.

After adopting the CRPD in 2006, the UN opened it for signature and ratification in 2007. In 2008, after 20 countries had ratified it, it entered into force. By ratifying the CRPD, countries make a commitment in international law to translate its principles into policy and practice. The Irish Government ratified the CRPD in 2018.

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<sup>133</sup> Birtha, M (2016) Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway  
[https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD\\_MBirtha\\_final\\_submission.pdf](https://aran.library.nuigalway.ie/bitstream/handle/10379/5349/PhD_MBirtha_final_submission.pdf)

<sup>134</sup> A 'convention' is a formal agreement between States. The generic term 'convention' is thus synonymous with the generic term 'treaty' <https://www.unicef.org/french/crc/files/Definitions.pdf>

<sup>135</sup> General Comment No. 7 from the UN Committee on the Rights of persons with disabilities (CRPD Committee) distinguishes DPOs, which are organisations "of" persons with disabilities, from organizations "for" persons with disabilities that provide services or advocate for persons with disabilities. In a DPO, persons with disabilities govern, lead and operate the DPO and form a majority of persons in the DPO. (The UN CRPD Committee is a body of independent experts set up to monitor CRPD implementation)

The Convention and its Optional Protocol entered into force in 2008. When a country ratifies the CRPD, it commits to realising human rights and fundamental freedom for persons with disabilities, in accordance with the CRPD. It has to establish mechanisms to ensure that persons with disabilities participate in decision-making about the issues that affect their lives and its quality and participate in the monitoring of the implementation of the Convention. The 50 Articles of the Convention address areas including health; education; employment; access to justice; liberty and personal security; independent living; access to information. See Appendix 3 for a list of the articles.

The UN Committee on the Rights of persons with disabilities is comprised of 18 members who serve in an individual capacity. States that have ratified the CRPD nominate individuals. States are obliged under the CRPD to submit reports to the CRPD Committee. After ratifying the CRPD, states submit an initial implementation report after two years and, thereafter, a report every four years to the Committee.<sup>136</sup> The aim of the process is to review the extent to which governments have aligned their national law, policy and practice with CRPD provisions. The Committee responds to the reports by commending good practice, outlining concerns and making recommendations on how states might make further progress in implementing the CRPD. The Committee develops general advice to clarify the implications of the CRPD and it issues its clarifications and advice in the form of General Comments.<sup>137</sup> The Committee's observations on the implementation of the articles of the CRPD are not legally binding on parties but they constitute the primary record of findings and recommendations concerning national implementation.<sup>138</sup> The Committee provides advice on UNCRPD implementation through inquiries and individual complaints under the Optional Protocol.

In summary, after ratification of the Convention, the Reporting Cycle in each country to the Committee involves the following:

- An initial state report.

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<sup>136</sup> Under Article 35 of the CRPD, each party to the convention must submit regular reports on the measures it has taken to implement the CRPD to the Committee on the rights of persons with disabilities

<sup>137</sup> The drafting of a general comment is a participatory process including consultations with a variety of stakeholders such as DPOs, the representative organizations of persons with disabilities, specialized agencies, NGOs, academia and human rights agencies.  
<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGDI1June2018.aspx>

<sup>138</sup>

[https://www.ohchr.org/\\_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/CRPD/16thsession/EuropeanUnionAgencyFundamentalRights.doc&action](https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/CRPD/16thsession/EuropeanUnionAgencyFundamentalRights.doc&action)

- Adoption of Committee's list of issues.
- Government's written replies (after ~2 months).
- Constructive dialogue between the government and UN Committee
- Concluding observations (recommendations) – ideally, government and other stakeholders including DPOs circulate them widely.
- Implementation of recommendations by state party, which provides an update to the Committee within a year of adoption of the concluding observations.
- Thereafter, with the submission of the periodic reports, the same cycle as outlined above ensues, which is adoption of the Committee's list of issues, government's written replies, constructive dialogue etc.

The CRPD requests that states parties consult with civil society, particularly DPOs, to prepare its country report. DPOs can also submit their own alternative or parallel report at the same time as the initial state report and, thereafter, at the same time as the periodic state reports, outlining their issues and recommendations. While State Parties are obliged to submit reports, the UN Committee values the DPO 'alternative', 'parallel or 'shadow' reports, which provide them with further information for their review. These reports represent a different narrative and balance the views of the State with those of the rights-holders.<sup>139</sup>

Before the CRPD Committee sends the State a list of issues and questions based on its concerns, DPOs can suggest issues that the Committee should ask the State. DPOs can give an oral presentation during the session in which the state adopts the list of issues drafted by the UN Committee. DPOs can give their own responses to the list of issues and questions within 2 months, in parallel with the State. DPOs can give an oral presentation during the constructive dialogue plenary session between the Committee and the State Party. Before the dialogue, and during the session, DPOs can try to meet with Committee members and, in particular, the country Rapporteur, to explain their priority issues and recommendations.

Before the Committee publishes its observations and recommendations, DPOs can identify the priority areas that need action and suggest recommendations to the Committee on issues discussed during the dialogue.<sup>140</sup> DPOs participation in the reporting cycle should involve all persons with disabilities, including persons

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<sup>139</sup> <https://mhe-sme.org/wp-content/uploads/2017/09/Toolkit-on-the-review-process-of-the-UN-CRPD.pdf>

<sup>140</sup> Leenknecht, AS (2016) The UN CRPD: key features [http://www.era-comm.eu/UNCRPD/e\\_learning/A/e\\_presentations/Leenknecht\\_Part\\_3/media/Print.pdf](http://www.era-comm.eu/UNCRPD/e_learning/A/e_presentations/Leenknecht_Part_3/media/Print.pdf)



with intellectual disabilities, persons with psychosocial disabilities, persons who are deaf, persons who are deafblind, persons with autism, persons under guardianship and persons living in institutions. The State report and answer to the list of issues, as well as submissions from DPOs and CSOs should reflect the views of women, children, older persons, migrants (refugees, illegal migrants), indigenous and ethnic minorities and LGBTI people with disabilities, from all across the country, both in rural and urban areas.<sup>141</sup>

### **An overview of CRPD Articles on participation**

Participation of DPOs as per Articles 4.3 and 33 of the CRPD involves DPOs and individuals with disabilities participating in developing and implementing legislation and policies to attain the CRPD principles and articles and monitoring CRPD implementation including the preparation of reports by State Parties.

The CRPD Preamble and Articles 3, 29, 32, and 35 of the CRPD also address participation of DPOs and individuals with disabilities in political and public life and in international cooperation. Article 29 of the CRPD, for example, states that participation is required on a political and public basis and that States must promote an environment where persons with disabilities and DPOs can participate in the conduct of public affairs on an equal basis with others. This includes through the activities of non-governmental organisations as well as through forming and joining DPOs.

In addition, Article 40 of the CRPD stipulates that States Parties shall meet regularly in a Conference of States Parties (COSP) to consider any matter with regard to CRPD implementation. A Conference of States Parties to the CRPD must include persons with disabilities and their DPOs in order to meet the commitments laid out in the CRPD.

In 2016, through the International Disability Alliance (IDA), civil society established a coordination mechanism to promote the meaningful engagement of all persons with disabilities in the Conference of States Parties.<sup>142</sup> The Civil Society Coordination Mechanism (CSCM) is a self-organizing, voluntary group of persons with disabilities, DPOs, non-governmental organizations and other civil society stakeholders committed to ensuring the implementation of Article 4.3 in the COSP. A Steering Committee comprised of 20 individuals leads the CSCM. It advocates for the meaningful inclusion of persons with disabilities in all stages of the Conference; selects speakers/civil society representatives in the Conference

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<sup>141</sup> Leenknecht, AS (2016) The UN CRPD: key features [http://www.era-comm.eu/UNCRPD/e\\_learning/A/e\\_presentations/Leenknecht\\_Part\\_3/media/Print.pdf](http://www.era-comm.eu/UNCRPD/e_learning/A/e_presentations/Leenknecht_Part_3/media/Print.pdf)

<sup>142</sup> <http://www.internationaldisabilityalliance.org/COSP#LinkCSCM>

through an open and transparent voting process, and organises the Civil Society CRPD Forum.

### **Article 4.3**

Article 4.3 of the CRPD sets out the need to adopt legislative, administrative and other measures to implement the rights recognised in the CRPD and to change laws, procedures and processes so that persons with disabilities access decision-making. Article 4.3(3) provides that in developing and implementing legislation and policies to implement the CRPD, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties “consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations”.<sup>143</sup> Interpretation of Article 4(3) includes that it has created a new space between states, DPOs and persons with disabilities. It presents opportunities and challenges for governments and for persons with disabilities and the disability movement. States have to work out what active and effective participation entails, establish effective partnerships between policy-makers and DPOs and decide how to support participation at all levels. They also have to decide when involvement should start.<sup>144</sup>

Embedding the principles of co-production partnerships is one way of putting Article 4.3 or the “Nothing about us without us” slogan of the Disabled People’s Movement into practice.<sup>145</sup> Co-production means inclusive working practices between experts by experience and organisations/ professionals. It is equal partnership and collaboration between both parties in order to improve service provision. Some examples are as follows:

England: The National Co-production Advisory Group (NCAG) composed of people who access services, carers and family members, works to co-produce services with the Think Local, Act Personal (TLAP) Partnership. TLAP is a national partnership of 50 health and care service organisations that work in community-based support and personalisation. It includes local and central government, the National Health Service and service providers and engages with

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<sup>143</sup> Article 4 of the CRPD sets out the need to adopt legislative, administrative and other measures to implement the rights recognised in the CRPD and the need to change laws, procedures and processes so that disabled people can access decision-making.

<sup>144</sup> Birtha, M (2017). The monitoring phase of UNCRPD implementation under Article 33: A unique opportunity to make disability rights real. Presentation at seminar for policy practitioners on EU disability law and the UNCRPD, Trier, 13–14 November 2017 [http://www.era-comm.eu/UNCRPD/kiosk/pdf/seminar\\_documents/s\\_c\\_417DV82.pdf](http://www.era-comm.eu/UNCRPD/kiosk/pdf/seminar_documents/s_c_417DV82.pdf)

<sup>145</sup> Griffiths, M for ENIL (2014) Implementing Article 4(3) of the UNCRPD [https://enil.eu/wp-content/uploads/2012/06/Fact-Sheet\\_Article4\\_FINAL.pdf](https://enil.eu/wp-content/uploads/2012/06/Fact-Sheet_Article4_FINAL.pdf)

people with care and support needs, carers and family members via NCAG. NCAG has a core group of 16-18 members, a flexible group of 20 people, and members available for email contact as well as some 'seldom heard' groups. People in the core and flexible groups receive pay for their contributions. Examples of NCAG involvement include working with the Skills Academy to develop a feedback tool about staff for people using services, providing representatives to the Professional Assembly of the College of Social Work and inputting into Social Care Institute for Excellence (SCIE).<sup>146</sup>

In addition to the UK's Equality 2025 project, England, Hammersmith & Fulham Council established a Disabled People's Commission (DPC) in 2016-2018 with ten DPC commissioners who self-identified as disabled people. The Commission researched barriers experienced by local people, developed a co-production approach to council policy including starting from the ideas of disabled residents and co-designing and delivery of services and submitted a report to cabinet, Nothing about Disabled People without Disabled People, published in June 2018. A new group of disabled residents, councillors and council officers are working to ensure that the report's recommendations become a reality.<sup>147</sup>

In Sweden, the Stockholm Cooperative on Independent Living (STIL) is a national and international model of user-run personal assistance services. It sits on government advisory bodies and networks, providing advice on personal assistance and on personal assistance legislation proposals and amendments. It is a member of the Assistance Forum for the Swedish Social Insurance Agency, providing information, ideas and arguments on proposals for new guidelines and other measures. It meets with the Board of Health, the Work Environment Authority and other government agencies through a network of Personal Assistance Providers. KFO, the largest employment organisation for personal assistance, consults STIL and, as an employer of personal assistants, STIL provides it with advice on guidelines and proposals.<sup>148</sup>

### **Article 33**

The purpose of Article 33, which the CRPD states is to supplement Article 4.3, is to create a compulsory national implementation structure to ensure that all the

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<sup>146</sup> [https://www.thinklocalactpersonal.org.uk/Browse/Co-production/National\\_Co-production\\_Advisory\\_Group/](https://www.thinklocalactpersonal.org.uk/Browse/Co-production/National_Co-production_Advisory_Group/) and [https://enil.eu/wp-content/uploads/2012/06/Fact-Sheet\\_Article4\\_FINAL.pdf](https://enil.eu/wp-content/uploads/2012/06/Fact-Sheet_Article4_FINAL.pdf)

<sup>147</sup> <https://www.lbhf.gov.uk/councillors-and-democracy/resident-led-commissions/disabled-people-s-commission>

<sup>148</sup> <https://www.independentliving.org/docs3/stileng.html> and [https://enil.eu/wp-content/uploads/2012/06/Fact-Sheet\\_Article4\\_FINAL.pdf](https://enil.eu/wp-content/uploads/2012/06/Fact-Sheet_Article4_FINAL.pdf)

CRPD articles becomes a reality. The national implementation structure will accomplish the following:

- Promote CRPD implementation by designating one or more entities in the government to deal with matters related to CRPD implementation and another entity to establish or designate a coordination mechanism to facilitate adoption of the proposed measures.
- Prepare initial and periodic reports with data based information for the UNCRPD Committee.
- Monitor periodically the extent of CRPD implementation.
- After a country ratifies the Optional Protocol to the UNCRPD, the national implementation structure needs to provide a complaints mechanism and mediation, establish programs of prevention, undertake litigation and support persons with disabilities to file a complaint to the CRPD Committee, etc.

Table 3 summarises the features of the Compulsory National Implementation Structure that comprises the following:

- A focal point/s and an optional, though recommended, coordination mechanism (33.1).
- A monitoring framework that includes an independent monitoring mechanism (33.2).
- Full participation of civic society in the implementation processes and, in particular, persons with disabilities and DPOs (33.3). Article 33.3 requires that persons with disabilities should be able to participate separate from the participation of DPOs if they so choose.

The focal point/s in government has the responsibility of developing national disability policies and implementation action plans. The implementation plan specifies actions under each Article and can specify indicators under each article along with a timeframe and identify who will carry out the actions and monitor indicators. Interpretations of focal points include the following:<sup>149</sup>

- It is an issue of internal public administration.
- The government formally designates one or more focal points, ideally close to the central authority.

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<sup>149</sup> Birtha, M (2017). The monitoring phase of UNCRPD implementation under Article 33: A unique opportunity to make disability rights real. Presentation at seminar for policy practitioners on EU disability law and the UNCRPD, Trier, 13–14 November 2017 [http://www.era-comm.eu/UNCRPD/kiosk/pdf/seminar\\_documents/s\\_c\\_417DV82.pdf](http://www.era-comm.eu/UNCRPD/kiosk/pdf/seminar_documents/s_c_417DV82.pdf)

- Suitable government departments might include that of justice that can deal with disability issues under a human rights model of disability.
- Focal point staff should be trained on CRPD provisions
- Adequate resources for the work of the focal point

**Table 3: Features of the CRPD Article 33 National Implementation Structure**

Art. 33 (1) CRPD	One or more focal point(s)
Art. 33 (1) CRPD	A coordination mechanism
Art. 33(2) CRPD	A monitoring framework including an independent monitoring mechanism
Art. 33(3) CRPD	Involve civil society in particular DPOs and individual persons with disabilities in monitoring

Article 33.1 does not specify which Government department should take on the focal point role. In many states, the focal point is the Social Affairs Ministry. In England, the Office for Disability Issues (a cross-governmental body) is the focal point while, in Ireland, it is the Department of Justice and Equality. In Northern Ireland, the Office of the First Minister and Deputy First Minister is the focal point while, in Finland, it is the Ministry of Social Affairs and Health together with the Ministry for Foreign Affairs and a civic organisation representative appointed by the coordination mechanism. In some States, the focal point organises a whole of government programme to ensure that DPOs and persons with disabilities, including children and families, are involved in decision-making. The focal point can promote capacity building and set up consultative committees that are open to representation from DPOs and persons with disabilities so that they interact with State authorities through the focal point as well as in other ways. The CRPD committee, in its feedback to Lithuania in 2016, recommended that it establish strong and efficient focal points responsible for CRPD implementation in each ministry and State institution.<sup>150</sup>

Article 33.1 recommends a coordination mechanism: “Give due consideration to the establishment or designation of a coordination mechanism within government

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<sup>150</sup> See Committee on the Rights of Persons with Disabilities (2016) Concluding observations on the initial report of Lithuania, given on 16<sup>th</sup> April 2016, paras 67-68, available at: [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLTU%2fCO%2f1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fLTU%2fCO%2f1&Lang=en)

to facilitate CRPD implementation in different sectors and levels”. While it is not required, it is best practice to have a coordination mechanism. When created, it can ensure consistent action and mainstream, coordinate and support CRPD implementation into action plans across government departments and sectors. In some countries, the focal point and the coordination mechanism are in the same Ministry or Department while, in others, they are distinct. Some countries have no coordination mechanism but set up ‘broad advisory bodies’ with the task of assisting and coordinating the work of focal points. In Finland, the coordination mechanism is the Advisory Board for the Rights of Persons with Disabilities established for this purpose under the Ministry of Social Affairs and Health. The advisory board promotes and coordinates national implementation of the CRPD. It draws up an action plan for each term that determines key national objectives in CRPD implementation and associated measures and monitoring.<sup>151</sup>

Article 33.2 establishes a monitoring framework including one or more independent monitoring mechanisms (IMM)<sup>152</sup>. The Office of the United Nations High Commissioner for Human Rights (UN-OHCHR) prepared a study on Article 33, after consultation with states, civil society organizations, and independent experts.<sup>153</sup> It stresses the importance of monitoring to assess whether countries are really adopting and applying appropriate measures that will make the CRPD a reality. Monitoring evaluates the results, provides feedback, fosters accountability and, over the long term, strengthens the capacity of parties to fulfil their commitments and obligations. The independent monitoring mechanism/s (IMM)<sup>154</sup> must be Paris-Principles<sup>155</sup> compliant. The Paris Principles

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<sup>151</sup> <https://www.humanrightscentre.fi/rights-of-persons-with-disabilit/national-monitoring-and-implemen/>

<sup>152</sup> While the wording of the English version of Article 33(2) seems to allow for non-independent bodies as long as there is one independent body, some argue that this is ‘against the spirit’ of Article 33.2 and that, all bodies in the framework should be independent.

<sup>153</sup> Office of the High Commissioner for Human Rights (OHCHR). Annual report of the United Nations High Commissioner for Human Rights and reports of the Office of the High Commissioner and the Secretary-General. Thematic study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities. A/HRC/10/48 (January 26, 2009). Available at: [www2.ohchr.org/english/issues/disability/docs/A.HRC.10-48\\_sp.doc](http://www2.ohchr.org/english/issues/disability/docs/A.HRC.10-48_sp.doc).

<sup>154</sup> While the wording of the English version of Article 33(2) seems to allow for non-independent bodies as long as there is one independent body, some argue that this is ‘against the spirit’ of Article 33.2 and that, all bodies in the framework should be independent.

<sup>155</sup> The Paris Principles, devised to establish the creation and functioning of independent national human rights institutions (NHRIs), have no binding nature but constitute a parameter for the creation of NHRIs. They require that States legally create independent mechanisms and outline NHRI responsibilities, composition and working methods.

are “principles relating to the status and functioning of national institutions for protection and promotion of human rights”.<sup>156</sup>

The purpose of the IMM is to promote, protect and monitor CRPD implementation. The CRPD Committee indicates that where there is a National Human Rights Institute (NHRI) that fulfils the independence requirement of Article 33.2, it should be part of the monitoring framework. In addition, the NHRIs should have sufficient funding to choose their staff and determine priorities and represent the diverse social forces that protect and promote human rights. Representatives of government departments can participate in an NHRI in an advisory capacity.

The German Institute for Human Rights carried out research for the Global Alliance of National Human Rights Institutions (GANHRI) in 2017 on the frameworks set up to fulfil the obligations of State Parties under Article 33.2 and Article 33.3 of the CRPD.<sup>157</sup> They sent a questionnaire to the NHRIs that belonged to GANHRI. Of the 78 A-status and 32 B-status NHRIs registered with GANHRI in 2017, 40 A-status NHRIs and 9 B-status NHRIs replied to the survey. The results show that a significant number of states parties have not yet taken a decision on how to construct the monitoring framework at the national level. However, a growing number of states are tasking NHRIs with implementing Article 33.2, particularly CRPD monitoring. NHRIs, in almost equal numbers, had sole responsibility and shared responsibility to promote, protect and monitor the implementation of the right of persons with disabilities. There are also states that have charged other institutions with the tasks under Article 33 of the CRPD. A comparison of the results of the 2017 survey with those of a similar survey conducted in 2011 indicated a trend towards nominating NHRIs either as the bearers of sole responsibility or of responsibility shared with others.

States create the Monitoring Framework and IMM in diverse ways. In some States, there is a single, existing independent monitoring mechanism such as an NHRI, ombudsman or equality body. Other states create new independent mechanisms while some create a framework that includes both existing and new

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<sup>156</sup> The Paris Principles, devised to establish the creation and functioning of independent national human rights institutions (NHRIs), have no binding nature but constitute a parameter for the creation of NHRIs. They require that States legally create independent mechanisms and outline NHRI responsibilities, composition and working methods.

<sup>157</sup> Aichele, V in the German Institute of Human Rights (2017) Analysis: Promote, Protect and Monitor 2017 Update Survey on Article 33 (2) of the Convention on the Rights of Persons with Disabilities [https://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/Publikationen/ANALYSE/Analysis\\_Promote\\_\\_Protect\\_and\\_Monitor.pdf](https://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/Publikationen/ANALYSE/Analysis_Promote__Protect_and_Monitor.pdf)

entities. In Italy and Slovenia a third of the members of the IMM are representatives of DPOs. States elaborate how they will promote, protect and monitor the implementation of the CRPD in different ways. FRA, the European Union Agency for Fundamental Human Rights, set out some examples in 2016, which included the following:<sup>158</sup>

- Promoting CRPD implementation
  - Awareness raising – e.g., organising and participating in events, publishing reports and other materials, communication activities, information campaigns.
  - Training and capacity building – e.g., production of CRPD guides, seminars and trainings, supporting DPOs to build up their monitoring capacities
  - Policy development e.g., supporting the preparation of action plans and other policy initiatives concerning the rights of persons with disabilities and CRPD implementation
- Protecting CRPD implementation – e.g., inquiring into potential non-compliance with the CRPD, handling complaints and, sometimes, imposing sanctions for CRPD violations. Some frameworks have a mandate to conduct monitoring visits to closed institutions, sometimes but not exclusively under their role as National Preventative Mechanism under the Optional Protocol to the UN Convention against Torture.
- Monitoring CRPD implementation – e.g., collecting thematic and statistical data on specific issues concerning the rights of persons with disabilities, reviewing national legislation, policies and programmes, making recommendations, and submitting reports and legal opinions to government and other authorities concerning CRPD implementation. Some frameworks monitor the implementation of national disability strategies and action plans.

Article 33.3 mandates full participation of civic society, in particular, DPOs and persons with disabilities, in the monitoring process of human rights. It states that the IMM should involve DPOs in its work. Point 35 of General Comment No. 7, states: “The Paris Principles require that DPOs/OPDs should either be represented in the independent mechanisms or be able to cooperate closely with these mechanisms, and preferably be appointed to their board, if such one exists.” In effect, DPOs should have a direct partnership with the Government to contribute to its processes. While the input of DPOs can take various forms, clear processes for representation and input are beneficial so that partnerships

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<sup>158</sup> Opinion of the European Union Agency for Fundamental Rights concerning requirements under Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities within the EU context



between DPOs and governments are effective. The CRPD expect governments to seek out DPOs input and fund the support costs of DPO representatives if there are not already existing funding mechanisms for DPOs in place.

When focal points, coordination and monitoring mechanisms are established, States determine how to fund the national implementation structure so that it can carry out its duties of promoting CRPD implementation and assessing its implementation. After a country ratifies the Optional Protocol, the State provides a complaints mechanism and mediation, establishes programs of prevention, undertakes litigation and supports persons with disabilities to file a complaint to the CRPD Committee, etc.

### **Challenges to implementing Article 4.3 and 33**

Many countries are taking time to work out how to develop and set up the Article 33 structure,<sup>159</sup> which will help deliver the CRPD. For example, Sweden ratified the CRPD and its optional protocol in 2008. The CRPD committee after reviewing its initial report in 2014, recommended that Sweden establish an independent mechanism based on the Paris Principles to monitor CRPD implementation. In order to establish an independent monitoring mechanism, the government appointed an inquiry in 2018, which submitted proposals on establishing a national human rights institution (NHRI) at the end of 2018.

National institutions build capacity over time. The European Network of Equality Bodies (EQUINET) and The European Network of National Human Rights Institutions (ENNHRI) recognise that equality bodies and NHRIs responsible for the monitoring, protection and promotion of the Convention need support to build skills and strategic capacity to engage with DPOs and the CRPD Committee, to begin to seek meaningful input from DPOs, to explore ways for securing the participation of DPOs in the engagement process with the CRPD Committee. EQUINET and ENNHRI provide training to this end including the strengthening of links and peer support among independent mechanisms including through the work of the ENNHRI's CRPD Working Group. One training event included equality bodies and NHRIs to reflect on how best to engage with DPOs; how to support DPOs to conduct their independent monitoring; how to build effective engagement with the CRPD Committee; to discuss the human and

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<sup>159</sup> As outlined this structure is to include focal point/s, an optional though highly recommended co-ordination mechanism, a CRPD monitoring framework with one or more independent monitoring mechanisms, and the participation of DPOs and persons with disabilities in all aspects of the structure.

financial resources needed to implement their mandate and engage with the CRPD Committee.<sup>160</sup>

In addition to governments being willing to engage in and grow participatory democracy, civil society must also be capable of engaging in policy and legislative processes to implement the CRPD. The CRPD vision is that of robust and participatory democracies where civil society can ensure that governments work steadily towards attaining equal rights for all. The CRPD requirement to include DPOs in implementing and monitoring rights, is premised on the existence of DPOs that understand and embrace their role as rights advocates. However, this is not always the reality globally and one must acknowledge and work at deciding how best to tackle the issue.

Challenges in achieving effective involvement and participation of persons with disabilities and DPOs are due to a range of factors that vary from country to country. Political, economic and social conditions has a significant impact on whether DPOs exist in the first place and how they operate. In countries where there is a long history of high levels of social spending and disability organizing, DPOs advocate successfully for laws and policies that promote the UNCRPD goals. However, when there is little support or funding, it is difficult for the third sector, including DPOs, to be a 'driving force' of social policies. Thus, relying on civil society to attain desired social change is possibly more challenging for countries with centralised governments and low levels of experience and support for civil society participation in policy and legislation and other co-production processes.

A major issue worldwide for third sector organisations including DPOs is uncertainty and fluctuations in funding. In times of economic austerity, governments often give 'value for money' more importance than experiential knowledge and this leaves DPOs more vulnerable. Research in the UK identified reductions in government funding, issues related to the marketization of social care services, competition from national charities and business organisations and a lack of business skills and professional structures to run dynamic and effective organisations as factors that militated against DPOs receiving funding. The author concluded that if DPOs are to survive, governments must move beyond mechanistic criteria for what constitutes a DPO and acknowledge changes both

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<sup>160</sup> EQUINET and ENHRI (2018) Training for equality bodies and National Human Rights Institutions on engagement with CRPD Article 33.2 Riga, 3-4 October 2018  
[http://equineteurope.org/wp-content/uploads/2018/08/concept\\_note\\_ennhri\\_equinet\\_joint\\_training\\_3-4\\_riga.pdf](http://equineteurope.org/wp-content/uploads/2018/08/concept_note_ennhri_equinet_joint_training_3-4_riga.pdf)

within and external to DPOs as well as changes within the disability community as a whole.<sup>161</sup>

DPOs in developing countries often address basic needs rather than advocate for rights. To address this, the international disability rights movement initiated global campaigns to encourage such DPOs to redefine themselves as rights advocates. Meyers and Lockwood (2014)<sup>162</sup> point out that changing organizations is not so easy, particularly when the political culture and socio-economic context does not change alongside them. They suggest that international donors should listen to grassroots voices that address local needs as well as providing them with resources and capacity building for advocacy and human rights work. While the CRPD is a universal human rights instrument that tends to work from the top down, civil societies develop from the bottom-up within specific cultures and contexts. The universal rights defined in the CRPD apply to all persons but civil society is particular. Thus, governments could profitably engage in dialogue with persons with disabilities and DPOs to understand how they can meet the needs of their members and how governments can support them in this endeavour. The international movement could encourage local organizations to set their own priorities and tailor training to them.<sup>163</sup> Meyers (2016)<sup>164</sup> suggested that when cross-national DPOs and donor countries ignore local DPOs needs and co-opt DPOs for human rights advocacy through processes that alter local groups and alienate its members, DPOs are likely to become less representative and responsive to local needs.

## **General Comment No. 7**

The CRPD Committee issues General Comments to clarify rights and legal obligations of States Parties and to provide guidance, suggestions and recommendations to foster CRPD implementation. This is in keeping with the practice of other human rights treaty bodies.<sup>165</sup> General Comments reflect the Committee's interpretation of the CRPD. The Committee clarifies the reporting

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<sup>161</sup> Wayne Carey, S (2019) Disabled People's User Led Organisations: Past, Present and a Secure Future? PhD, Anglia Ruskin University, Faculty of Health, Education and Medicine

<sup>162</sup> Meyers, S., Lockwood, E (2014) A Tale of Two Civil Societies: Comparing disability rights movements in Nicaragua and Uruguay, *Disability Studies Quarterly*, 34 (4) <https://dsq-sds.org/article/view/3845/3804>

<sup>163</sup> *ibid*

<sup>164</sup> Meyers, S. (2016) NGO-ization and Human Rights Law: The CRPD's Civil Society Mandate. *Laws* 5: 21. <https://www.mdpi.com>

<sup>165</sup> General Comment No. 7 can be accessed with the other six General Comments issued by the Committee at <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>

duties of State parties with respect to certain provisions and suggests approaches to implementing treaty provisions. While General Comments are not legally binding, they have an authoritative character with a legal basis. The CRPD lays down legal obligations and the Committee's General Comments provides analysis and guidance on how to arrive at approaches to law and policy-making that will deliver the required changes. The goal is to establish processes and norms in a culture where "persons with disabilities still face significant attitudinal, physical, legal, economic, social and communication barriers to participate in public life".<sup>166</sup>

In 2018, the CRPD Committee identified a gap between the goal and the spirit of articles 4 (3) and 33 (3) and the degree to which State parties had implemented them.<sup>167</sup> The Committee considered that the gap was "due, among other things, to the absence of meaningful consultation with and involvement of persons with disabilities, through their representative organizations, in the development and implementation of policies and programmes". To address the gap, the CRPD Committee issued General Comment No. 7 on Articles 4.3 and 33 in 2018 following consultation on a draft. It addresses the participation of persons with disabilities and DPOs in the implementation and monitoring of the Convention. It advises that everyone should read and understand Article 33 as supplementing article 4.3<sup>168</sup>, explains their implications, defines DPOs and addresses their scope.<sup>169</sup> It distinguishes organizations "of" persons with disabilities (DPOs) from organizations "for" persons with disabilities, which provide services for or advocate on behalf of persons with disabilities. "Civil society organizations" comprise organizations such as research institutes, service provider organisations and other private stakeholders while DPOs are a specific type of civil society organization. The distinction made between DPOs, which are organisations of persons with disabilities and organisations for persons with disabilities is in line with Oliver's typology of disability organisations. He devised this typology in 1984 and further developed it in 1990.<sup>170</sup> Table 4 illustrates his typology where Type 1 and Type 2 organisations are for persons with disabilities while types 3, 4 and 5 are organisations of persons with disabilities.

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<sup>166</sup> Point 5, General Comment No. 7, Committee on the Rights of persons with disabilities 2018

<sup>167</sup> Ibid Point 8,

<sup>168</sup> Ibid No. 34,

<sup>169</sup> Ibid No. 10-12,

<sup>170</sup> Oliver, M. (1984), 'The Politics of Disability', *Critical Social Policy*, 4 (11), pp. 21–32; see: Callus, A.M. (2013), 'From "for" to "of": A typology of Maltese disability organisations', *Disability and Society*, 29 (1), p. 1 as cited by Magdolna BIRTHA (2016) *Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring*, PhD Thesis, NUI, Galway

**Table 4: Oliver’s typology of disability organisations<sup>171</sup>**

For persons with disabilities	Type 1	Partnership/Patronage	Partnership with government
For persons with disabilities	Type 2	Economic/ Parliamentarian	Initially focused on adequate income for persons with disabilities
DPOs	Type 3	Consumerist/Self-help/Self-advocacy	Improve lives of members
DPOs	Type 4	Populist/Activist	Strong human rights focus
DPOs	Type 5	Umbrella/Co-ordinating	Strategic

Point 11 of General Comment No. 7 outlines characteristics of DPOs as follows:

- Employ, are represented by, and appoint persons with disabilities and are established to act, express, promote, pursue and/or defend the rights of persons with disabilities.
- Can be local, national, regional or international in scope and can operate as individual organizations, coalitions or umbrella organizations to provide a coordinated voice in interactions with public authorities, international organizations and private entities, etc.
- Not generally affiliated to a political party and independent from public authorities and non-governmental organizations of which they may form part.
- May represent one or more constituencies based on actual or perceived impairment or can be open to membership of all persons with disabilities.
- Represent groups of persons with disabilities reflecting diversity of their backgrounds.
- Organizations of women and children with disabilities and persons living with HIV/AIDS are organizations of persons with disabilities under the CRPD.

Point 12 of General Comment 7 identified various types of DPOs, which include:

- Umbrella DPOs are coalitions of representative organizations of persons with disabilities that speak on behalf of member organizations on matters of mutual interest. To be open, democratic and represent the diversity of persons with disabilities, they should accept all DPOs as members

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<sup>171</sup> Cited by Birtha, M (2016) in Making the new space created in the UN CRPD real: Ensuring the voice and meaningful participation of the disability movement in policy-making and national monitoring, PhD Thesis, NUI, Galway

- Cross-disability organizations, composed of persons representing the diversity of impairments, organize at local, regional, national and international levels
- Self-advocacy organizations represent persons with disabilities and advocate for the rights of persons with disabilities, especially persons with intellectual disabilities. Their establishment, with extensive support to enable members to express their opinions, is important for all forms of participation
- Organizations including family members and/or relatives of persons with disabilities facilitate, promote and secure the interests and support the autonomy and active participation of relatives with intellectual disabilities, dementia and/or children with disabilities, when these persons want their families to support them as united organizations. In such cases, these organizations should be included in consultation, decision-making and monitoring processes
- Organizations of women and girls with disabilities and the diversity of women and girls with disabilities should include all types of impairments
- Organizations and initiatives of children and young persons with disabilities are fundamental for their participation in public and community life and for others to respect their rights and freedom of expression and association. Adults have a supportive role to play in promoting an environment that enables children and young persons to act in initiatives and organizations

### **The scope and the development of DPOs**

The CRPD emphasises that DPOs are organisations **of** persons with disabilities as distinct from disability charities and as distinct from other disability organisations **for** persons with disability. They are civil society (third sector) organisations **of** persons with disabilities. The CRPD Committee emphasises the fact that they are (largely) organisations **of** persons with a disability. A defining characteristic of DPOs is that a majority of persons with disabilities form the management, staff and volunteers and also their members and user groups. While organisations **of** parents and relatives can support persons with disabilities, it is important to ensure that persons with disabilities are and remain in full control of decisions concerning issues relating to them and that they get to speak their mind independently.

The disability movement has promoted and strengthened DPOs in many countries. The disability movement has an international structure and, in some countries, national and local level structures. These structures facilitate society hearing and supporting the voice of persons with disabilities.<sup>172</sup> Some DPOs are

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<sup>172</sup> Hurst R (1999) Disabled People's Organisations and Development: Strategies for Change. Chapter 3 in Stone E. (ed.) 1999: Disability and Development: Learning from action and research

representative organisations of persons with disabilities. There are national and international DPO federations that represent specific group interests such as, for example, a federation of deaf persons. National cross-disability DPO federations represent persons with various disabilities. To fulfil their function well, these DPOs need transparent structures, organisational and advocacy capacity, and the clear goal of fulfilling their representative tasks effectively. Cross disability and specific international federations of DPOs build their capacity and that of other DPOs by sharing experiences, challenges and solutions and sometimes they strengthen the capacity of national DPOs in countries in the developing world.<sup>173</sup> Some countries fund representative DPOs in the developing world. The EU has ratified the UNCRPD and therefore has obligations too under it and it provides financial support through an annual grant to a number of EU-level DPOs and other NGOs to make their participation in EU-level processes easier.<sup>174</sup>

The emphasis in the CRPD is on DPOs as rights advocates, who can educate their members and communities regarding their rights and hold governments accountable for the fulfilment of their rights as full and equal citizens. Meyers and Lockwood (2014) explore how the obligation in the CRPD to include DPOs in the definition, implementation, and monitoring of rights presumes the existence of DPOs and other disability groups and networks that understand and embrace their role as rights advocates. However, this is not the reality in all countries.

The international working group who wrote the CPRD anticipated that DPOs would focus on the implementation of human rights, which is in keeping with the current global notion that civil society is the way to attain social change. Civil society is a broad concept - "third sector" and wide-ranging non-profit, voluntary associations encompassing private aspects of life through to the most public of functions. In the context of human rights, however, a narrower definition identifies civil society organisations as actors that give voice to the powerless by scrutinizing the implementation of human rights, report violations of human rights

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on disability in the majority world, Leeds: The Disability Press. p.25-35 as cited by Howard, A (2013) Placing Disability on the Policy Agenda: An Assessment of Participation in International Policy Processes by Disabled People's, MA Thesis in Development and Emergency Practice, Oxford Brookes University  
[https://www.brookes.ac.uk/uploadedfiles/faculty\\_of\\_technology,\\_design\\_and\\_environment/school\\_of\\_architecture/site\\_assets/documents/amy-howard-ma-dissertation.pdf](https://www.brookes.ac.uk/uploadedfiles/faculty_of_technology,_design_and_environment/school_of_architecture/site_assets/documents/amy-howard-ma-dissertation.pdf)

<sup>173</sup> P. 34, Handicap International (2011) Support to organisations representative of persons with disabilities. [http://www.hiproweb.org/uploads/tx\\_hidrtdocs/SupportToDPO.pdf](http://www.hiproweb.org/uploads/tx_hidrtdocs/SupportToDPO.pdf)

<sup>174</sup> <https://ec.europa.eu/social/main.jsp> These organisations include the European Disability Forum, Inclusion Europe, Mental Health Europe, European Union of the Deaf, Autism Europe, European Blind Union and the International Federation for Spina Bifida and Hydrocephalus. Not all these organisations are DPOs

abuses and campaign for the development of human rights standards (UN-OHCHR, 2007, p. iii). This is the understanding of civil society in the CRPD: civil society including DPOs will keep pressure on governments until they find the way to grant equal rights to persons with disabilities. In the 1970s and 1980s, disability movements in the USA and Europe pushed governments to change their laws and improve their policies. In 2002, the CRPD working group argued that disability NGOs or amalgam of NGOs were needed with a mandate to monitor human rights developments and to engage in local education programmes on rights and disability. To this end, the international disability rights movement and international organisations have initiated global campaigns to encourage grassroots DPOs to redefine themselves. For some DPOs, holding governments accountable for the implementation of the CRPD is a natural progression in their development. For other DPOs, formed for the provision of services and social support, advocacy is the opposite of what they have always done. While the rights defined in the UNCRPD are universal rights that apply to all persons with disabilities everywhere, civil society is something that is particular. No matter how international organizations define it, civil societies reflect the culture and realities of particular localities (Meyers and Lockwood, 2014).<sup>175</sup>

Meyers (2016) points out that cross-national DPOs and donor countries and organisations interested in human rights can ignore local DPOs needs, their context and specific knowledge, and co-opt them by providing funds for narrowly understood human rights advocacy without acknowledging other urgent local issues<sup>176</sup>. When outside actors co-opt NGOs through processes that alter local groups and alienate members, these organisations become less representative and responsive to local needs and interests. International organizations focused on supporting CRPD implementation should try to ensure that they also hear grassroots voices and address local needs. National DPOs that work at regional and local levels encourage cooperation, solidarity and understanding; increase their accountability to members; improve information sharing to grassroots level avoids interventions that do not affect the lives of persons with disabilities or impact on only a very small number of people.<sup>177</sup>

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<sup>175</sup> Myers, S., Lockwood, E (2014) A Tale of Two Civil Societies: Comparing disability rights movements in Nicaragua and Uruguay, *Disability Studies Quarterly*, 34 (4) <https://dsq-sds.org/article/view/3845/3804>

<sup>176</sup> Meyers, Stephen. 2016. NGO-ization and Human Rights Law: The CRPD's Civil Society Mandate. *Laws* 5: 21. <https://www.mdpi.com>

<sup>177</sup> *ibid*



Research by Meyer and Lockwood (2014)<sup>178</sup>, comparing and contrasting DPOs and the disability movement in Nicaragua and Uruguay, support their hypothesis that certain societies will demonstrate a better fit with the DPO model outlined in the CRPD and exported by international NGOs. In Uruguay, a long history of high levels of social spending and disability organizing enabled DPOs to advocate successfully for progressive laws. The deaf community, however, implemented their own, separate advocacy strategies to ensure a fairer distribution of public resources. In Nicaragua, a disability rights coalition dismissed international expectations in favour of continuing to follow traditional civil society expectations to provide services. The authors concluded that the international movement should allow local organizations to set their own priorities rather than imposing top-down civil society training, “Rights advocacy is important, but civil societies develop within particular cultures and in response to a variety of socioeconomic conditions. One size may not fit all. It is important to provide resources to persons with disabilities and their representative organizations to advocate for their members. But, a dialogue should be opened up in order to understand how civil society can be supported in a variety of contexts and what measures can be taken for them to meet the needs of their members”. Changing organizations is not easy, especially if the political culture and socioeconomic context does not change with them. The CRPD is a universal human rights instrument that disseminates norms from the top down while civil societies are usually from the bottom-up, developing within particular cultures and contexts.<sup>179</sup>

Such caveats and considerations need to be borne in mind by countries as they implement the CRPD.

### **International support for DPOs to engage in CRPD implementation<sup>180</sup>**

The CRPD recognizes that international cooperation supports national efforts to implement States Parties’ obligations. States Parties cooperate internationally through partnerships with other States, and/or with relevant international and regional organizations and civil society in support of national measures to give effect to the CRPD. Specifically, Article 32 identifies a range of measures that States can take within the framework of international cooperation:

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<sup>178</sup> Myers, S., Lockwood, E (2014) A Tale of Two Civil Societies: Comparing disability rights movements in Nicaragua and Uruguay, *Disability Studies Quarterly*, 34 (4) <https://dsq-sds.org/article/view/3845/3804>

<sup>179</sup> *ibid*

<sup>180</sup> <https://www.miusa.org/news/2015/RightsNow>

- Capacity building, including through the exchange and sharing of information, experiences, training programs and best practice.
- Research programs and the facilitation of access to scientific knowledge.
- Technical and economic assistance, including the facilitation of access to accessible and assistive technologies.

In addition, Article 32 states “that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities,” Thus Article 32 has important provisions not only for State Parties, but also for bilateral and multilateral development partners.<sup>181</sup> The inclusion of persons with disabilities in development is pertinent not only to improving their and their families’ welfare, but it also has important ramifications for the achievement of international global development goals, such as the Sustainable Development Goals.

Founded in 1981, Mobility International USA (MIUSA) is a national American non-profit cross-disability NGO led by a woman with a disability. Its headquarters are in Oregon. It focuses on international exchange and development as a tool for improving the lives of people with disabilities globally and forms advocates, including women, who contribute to the international disability rights movement.

Dunn and Sygall (2014: 49) explore some of the successful strategies of MIUSA for bridging the gap between the disability and humanitarian communities and increasing leadership capacity within the disability community, especially among women.<sup>182</sup> An informal survey of MIUSA’s international network of 176 disabled women leaders in 2012 highlighted that MIUSA alumni are a powerful and largely untapped resource for the humanitarian sector (Dunn and Sygall, 2014: 51). As a key strategy for promoting disability inclusion, MIUSA has built leadership capacity within the disability community with a focus on the empowerment of women with disabilities. Its signature international women’s leadership training is the Women’s Institute on Leadership and Disability (WILD) programme. This programme brings up to 30 women with disabilities together for an intensive 21-

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<sup>181</sup> Lord, J., Posarac, A., Nicoli, M., Peffley, K., McLain-Nhlapo., Keogh May, M (2010) Disability and International Cooperation and Development: A review of policies and practices DISABILITY <https://dochas.ie/sites/default/files/Disability%20and%20International%20Cooperation%20and%20Development.pdf>

<sup>182</sup> Dunn, S., & Sygall, S. (2014). Women with disabilities leading the way toward inclusive emergency response. In D. Mitchell & V. Karr (Eds.), *Crises, Conflict and Disability: Ensuring Equality*. (pp. 49-57). London: Routledge as cited by Roz Price (2018) Strengthening participation of people with disabilities in leadership roles in developing countries [https://assets.publishing.service.gov.uk/media/5b18fd1440f0b634c0c590d7/Strengthening\\_participation\\_of\\_people\\_with\\_disabilities\\_in\\_leadership\\_roles.pdf](https://assets.publishing.service.gov.uk/media/5b18fd1440f0b634c0c590d7/Strengthening_participation_of_people_with_disabilities_in_leadership_roles.pdf)

day leadership programme. Part of this programme is the four-day Gender, Disability and Development Institute (GDDI), in which representatives of international development and humanitarian agencies meet with WILD delegates to focus on inclusion of women with disabilities in development and humanitarian efforts (Dunn and Sygall, 2014: 52). MIUSA provides technical assistance on disability inclusion to development and humanitarian agencies. A component of MIUSA's inclusive development technical assistance work was to utilise the expertise of local women leaders with disabilities who were alumni of the WILD programme. For example, in Colombia, MIUSA reached out to Beatriz Satizabel, who participated in the 2003 WILD training, after which she went on to work for international NGOs in her country. In 2009, Satizabel, in collaboration with a law university, persuaded the Colombian government to amend laws to protect the rights of people with disabilities displaced by the civil conflict. Dunn and Sygall (2014: 56-57) make the following recommendations for including women with disabilities in emergency response, which are also relevant for broader inclusion:

- Reach out to women with disabilities. Working directly with DPOs and disabled women's groups is vital. MIUSA has an online searchable database of over 1,000 DPOs as well as personal contacts through its alumni network
- Promote professional development opportunities for women with disabilities
- Take action to be included in existing programmes. Women with disabilities are catalysts for change. Encouraging women with disabilities to take a proactive approach to inclusion, rather than waiting for the programmes to change, will accelerate inclusion

One of MIUSA's projects, the Right Now Project, is to assist DPOs globally in ensuring that governments bring their national law into line with the CRPD. It identifies DPOs that are trying to promote the enforcement of national law in line with the CRPD and works with them. While many countries have enacted national disability rights laws, they have limited effect at mitigating discrimination if there are few or no implementation measures, such as policies, standards and political advocacy training, for DPOs. 'Right Now' provides technical assistance and mentorship in person and via video, phone and email to DPO leaders. DPOs have access to an accessible online resource that offers practical tools in four languages and international sign. MIUSA administers the Right Now project with three USA partners:

- Disability Rights Education and Defense Fund (DREDF), a disability-led, organization at the forefront of U.S. disability civil rights law and policy
- International Foundation for Electoral Systems (IFES), a global leader in democracy promotion and good governance

- U.S. International Council on Disabilities (USICD), a disability-led organization committed to advocacy and action to promote the global disability rights agenda

The budget for the Right Now project was \$3,167,216 for 5 years (2014 to 2018). During this time, the project worked with DPOs in Armenia, Kenya, Guatemala, Mexico, Peru, and Vietnam. Between 2015 and 2018, MIUSA provided consultation and training to 250 DPOs in the six countries. Over 1,000 persons with disabilities received technical training. Technical assistance includes policy advocacy strategy, engaging political candidates, training lawyers, using the media, and advice on how to file disability discrimination complaints. It provides mentorship to help DPOs coordinate their country plans to strengthen legislation and increase political participation and to adapt plans to the local political and legal contexts. The focus may be on disability rights or on specific laws, such as health care and deinstitutionalization. This support has enabled DPOs to influence public policy, for example, to undertake a disability discrimination prosecution in Guatemala or ensure the incorporation of their recommendations into a National Accessibility Plan in Peru. It encourages DPOs to explore opportunities for networking. The project is seeking further funding to provide more assistance in the countries where it is working and to expand into new countries.

There are many international DPOs. The International Disability Alliance (IDA) is a network of global DPOs and, since 2007, regional DPOs and their families. Established in 1999, its aim is to promote the effective and full implementation of the UN CRPD worldwide, as well as compliance with the UN CRPD within the UN system, through the coordinated involvement of representative organisations of persons with disabilities at the national, regional and international levels. The IDA Secretariat in Geneva and New York carry out the organisation's day-to-day activities. IDA works to ensure that the way the 2030 Agenda and its Sustainable Development Goals are realised aligns with the UN CRPD. It supports DPOs in engaging with UN human rights processes in Geneva and New York, including the Treaty Bodies, Universal Periodic Review and Human Rights Council. It supports DPOs at national and regional levels through training and disseminating resources and information.<sup>183</sup>

The International Disability and Development Consortium is another global consortium of DPOs, disability and development NGOs, mainstream development NGOs supporting disability and development work in more than 100 countries.<sup>184</sup>

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<sup>183</sup> <http://www.internationaldisabilityalliance.org/content/history>

<sup>184</sup> <https://www.iddcconsortium.net>

## Appendix 5: Recommendations to States by UN Committee on implementing Article 4.3.

This appendix looks at some recommendations for a selection of countries from the monitoring of the Committee on the Rights of Persons with Disabilities in respect of Article 4.3 of the UNCRPD.

Article 4.3 reads as follows; *In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations (DPOs).*

Country & Report	Date	Recommendations with reference to Art. 4.3 in Concluding Observations
Australia Combined 2 <sup>nd</sup> & 3 <sup>rd</sup> periodic reports	20 Sept 2019	In close consultation with and with the effective participation of diverse DPOs, ensure that the National Disability Agreement and the national disability strategy receive adequate resources; an implementation plan with measurable goals; a robust monitoring mechanism; a formal performance-reporting framework; evaluation, governance and accountability requirements, including through the implementation of the recommendations made by the Productivity Commission.
Spain Combined 2 <sup>nd</sup> & 3 <sup>rd</sup> periodic reports	29 March 2019	Ensure the continued involvement of and meaningful consultation with various DPOS, including but not limited to those representing women, children, refugees and asylum seekers, lesbian, gay, bisexual, transgender and intersex persons, persons with psychosocial disabilities or with intellectual, hearing or visual impairments, persons living in rural areas and persons in need of high levels of support, in the designing and amending of new and current laws, policies and programmes to ensure their compliance with the Convention, in line with the Committee's general comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention;

Country & Report	Date	Recommendations with reference to Art. 4.3 in Concluding Observations
Poland Initial report	18 Sept 2018	<p>Ensure active and full-scale involvement and meaningful consultations with various representative DPOs when designing new laws and strategies to ensure that legislation complies with the Convention. Also, ensure involvement and consultation with DPOs and in the implementation and monitoring of and reporting on the Sustainable Development Goals.</p> <p>Develop, with the wide participation of representative DPOs, a strategy and action plan for the implementation of obligations under the Convention, ensuring a comprehensive paradigm shift from a charity model to the human-rights model of disability throughout national, regional, local and sectoral policies, regarding persons with disabilities as human rights holders.</p> <p>Ensure a disability assessment that fully incorporates a human-rights model of disability and takes a human rights-based approach by, inter alia, involving DPOs in the design of disability assessment mechanisms; engaging persons with disabilities in generating the information on which disability assessments are made; eliminating multiple methods of assessment and making information on assessment requirements accessible and user-friendly</p>
Norway Initial report	4 April 2019	Provide sustainable financial support for DPOs.
UK of Great Britain & NI Initial Report	29 Aug 2017	<p>Allocate financial resources to support DPOs, including women and children with disabilities, and develop mechanisms to ensure the inclusive, strategic and active involvement of DPOs, including women, children and intersex persons, in the planning and implementation of all legislation and measures that affect the lives of persons with disabilities</p> <p>Establish mechanisms to secure the full participation of DPOs in the design and implementation of strategic policies aimed at implementing the Convention across the State party, through objective, measurable, financed and monitored strategic action plans.</p>
Canada initial report	10 April 2017	<p>Establish formal and permanent mechanisms for consulting with representative DPOs in an effective and result-oriented manner at all levels of administration relating to the comprehensive implementation of the Convention</p> <p>Take measures, including specific budget allocations, to strengthen the advocacy roles of DPOs, including organizations of women with disabilities, children with disabilities, persons with psychosocial and/or intellectual disabilities and persons with neurodegenerative conditions, including Alzheimer's, dementia and multiple sclerosis.</p>

Country & Report	Date	Recommendations with reference to Art. 4.3 in Concluding Observations
Italy initial report	1 Sept 2016	<p>Establish a permanent consultative body that effectively and meaningfully consults with persons with disabilities through their representative DPOs in the development of all laws, policies and programmes</p> <p>Ensure that a broad range of persons with disabilities that reflect the diversity of people’s backgrounds, including age, sex, faith, race, sexual orientation, migrant status and impairment groups, meaningfully participate in an inclusive and accessible manner in direct decision-making processes that affect the lives of persons with disabilities at all levels and within all sectors of the State party.</p>
Lithuania initial report	18 April 2016	<p>Develop, adopt and implement a strategy aimed at achieving the full inclusion of DPOs in all political decision-making processes relating to matters affecting persons with disabilities, from the early stages and across all sectors, including in relation to the implementation and monitoring of the Sustainable Development Goals</p> <p>Provide sufficient financial support to build the capacity and enable the autonomous participation of DPOs in all decision-making processes.</p>
EU initial report	3 Sept 2015	Set up a structured dialogue for persons with disabilities and their representative organisations in all EU decision-making processes, with an independent budget and sufficient funding for consultation with and the participation of persons with disabilities.
New Zealand initial report	29 Sept 2014	No recommendations re Art. 4.3
Denmark initial report	2 Oct 2014	Governments of the Faroe Islands and of Greenland adopt dedicated disability policy action plans to effectively implement the Convention and Government of Greenland support the work of representative DPOs to ensure their effective participation in consultations on and implementation of the Convention.
Sweden initial report	11 April 2014	No recommendations re Art. 4.3
Germany initial report	13 April 2015	Develop frameworks for the inclusive, comprehensive and transparent participation of representative DPOs, including those experiencing intersectional discrimination, regarding the adoption of legislation, policies and programmes for the implementation and

<b>Country &amp; Report</b>	<b>Date</b>	<b>Recommendations with reference to Art. 4.3 in Concluding Observations</b>
		monitoring of the Convention. Provide resources to facilitate the participation of such organizations, especially smaller self-advocacy organizations



## **Appendix 6: Recommendations to States by UN Committee on implementing Article 33**

This appendix looks at the recommendations of the Committee on the Rights of Persons with Disabilities in respect of Article 33 of the UNCRPD for a selection of countries and the EU.

Article 33 reads as follows:

- 1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.*
- 2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.*
- 3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.*

<b>Country &amp; Report</b>	<b>Date</b>	<b>Recommendations with reference to Art. 33 in Concluding Observations</b>
Australia Combined 2 <sup>nd</sup> & 3 <sup>rd</sup>	20 Sept 2019	Revise existing laws or enact new laws, including a national comprehensive human rights law, to expand and strengthen the scope and power of the Australian Human Rights Commission to perform the task of independently monitoring the implementation of the Convention, in line with article 33 (2) of the Convention and the Committee's general comment No. 7.

Country & Report	Date	Recommendations with reference to Art. 33 in Concluding Observations
periodic reports		<p>Establish a formal monitoring mechanism under the National Disability Strategy that includes the Office of Disability Strategy, as recommended by the Senate Standing Committee on Community Affairs in 2017, ensuring effective coordination between the federal and state levels.</p> <p>Ensure sustainable and adequate funding for the meaningful engagement of persons with disabilities and their representative DPOs in the implementation and monitoring of the Convention.</p>
Spain Combined 2 <sup>nd</sup> & 3 <sup>rd</sup> periodic reports	29 March 2019	<p>Strengthen the capacity of the Spanish Committee of Representatives of Persons with Disabilities and its role as an independent monitoring mechanism for the implementation of the Convention, and provide adequate resources and funding for its functioning.</p>
Poland Initial report	18 Sept 2018	<p>Designate a cross-sectoral authority to coordinate and lead the mainstreaming and implementation of the rights of persons with disabilities in all sectors and at all levels;</p> <p>Strengthen the capacity of the Office of the Commissioner for Human Rights as the independent authority responsible for the promotion, protection and monitoring of the implementation of the Convention, in providing it with adequate legal bases and allocating it sufficient resources and funding to allow it to discharge its mandate effectively and independently;</p> <p>Ensure the comprehensive and effective involvement of DPOs in monitoring tasks under the Convention, and provide them with the funding necessary for that purpose.</p>
Norway Initial report	4 April 2019	<p>No recommendations re Art. 33</p>
UK of Great Britain & NI	29 Aug 2017	<p>Set up an appropriate coordinating structure of focal points with sufficient funding to strengthen the implementation of the Convention under all devolved governments and territories under its jurisdiction and/or control.</p> <p>Ensure in all its entities the independence of, and provide sufficient funding for, both established monitoring frameworks and representative DPOs to enable them to monitor the implementation of the Convention across the State party, taking into account the guidelines on independent monitoring frameworks and their participation in the work of the Committee</p>

Country & Report	Date	Recommendations with reference to Art. 33 in Concluding Observations
		Involve and financially support civil society organizations, in particular representative DPOs, in the preparation of its periodic report.
Canada Initial Report	10 April 2017	No recommendations re Art. 33
Italy initial report	1 Sept 2016	Immediately establish and implement an independent monitoring mechanism that adheres to the principles relating to the status of national institutions for the promotion and protection of human rights (the Paris Principles), and that it provide adequate funding for its functioning and the full involvement of representative DPOs in its work.
Lithuania initial report	18 April 2016	<p>Take the necessary steps to empower and enable the Ministry of Social Security and Labour to coordinate CRPD implementation.</p> <p>Establish strong and efficient focal points within each ministry and State institution responsible for CRPD implementation.</p> <p>Remove the Council for the Affairs of the Disabled from the independent monitoring framework and, in consultation with DPOs, expedite the establishment of an independent monitoring mechanism that is in compliance with the Paris Principles and that has the required expertise and access to sufficient resources in accordance with article 33 (2) of the Convention</p> <p>Adopt legislation to guarantee the full participation of representative organizations of persons with disabilities in the implementation, coordination and monitoring of the Convention.</p>
EU initial report	3 Sept 2015	<p>Decouple the role of the European Commission in the implementation and monitoring of the Convention by removing it from the independent monitoring framework to ensure compliance with the Paris Principles. (The European Commission was both a focal point (art. 33.1) for implementation and a mechanism for monitoring the implementation (art. 33.2) of the Convention.</p> <p>Ensure that the framework has adequate resources to perform its functions.</p> <p>Consider designating focal points in each EU institution, body and agency and establishing an inter-institutional coordination mechanism for the implementation of the Convention.</p> <p>Adopt a comprehensive strategy to implement the Convention across all EU institutions and Member States with a monitoring mechanism, budget and timeframe.</p>

Country & Report	Date	Recommendations with reference to Art. 33 in Concluding Observations
New Zealand initial report	29 Sept 2014	No recommendations re Art. 33
Denmark initial report	2 October 2014	Enable civil society and, in particular, representative DPOs, to fully and regularly participate in monitoring of the implementation of the Convention. Take the necessary measures for the establishment or designation of a coordination mechanism, and of an independent monitoring mechanism, in the Faroe Islands. The Committee also recommends that the Government of the Faroe Islands establish a human rights institution for the promotion and protection of human rights, in accordance with the Paris Principles.
Sweden initial report	11 April 2014	Establish an independent monitoring mechanism to fulfil effectively the obligation enshrined in the Convention in accordance with the Paris Principles.
Germany initial report	13 April 2015	<p>Consolidate the institutional structures in accordance with article 33 (1) of the Convention and formally implement the designation of focal points and their counterparts in the different areas of application of the Convention in all Länder</p> <p>Reinforce the necessary resources and conditions for the independent activity of focal points, including the legal status of all Land Commissioners for Matters Relating to Disabled Persons</p> <p>Strengthen the capacities of the independent monitoring mechanism in accordance with article 33 (2), and ensure the availability of resources for more comprehensive and effective monitoring at the Land and municipal levels.</p>