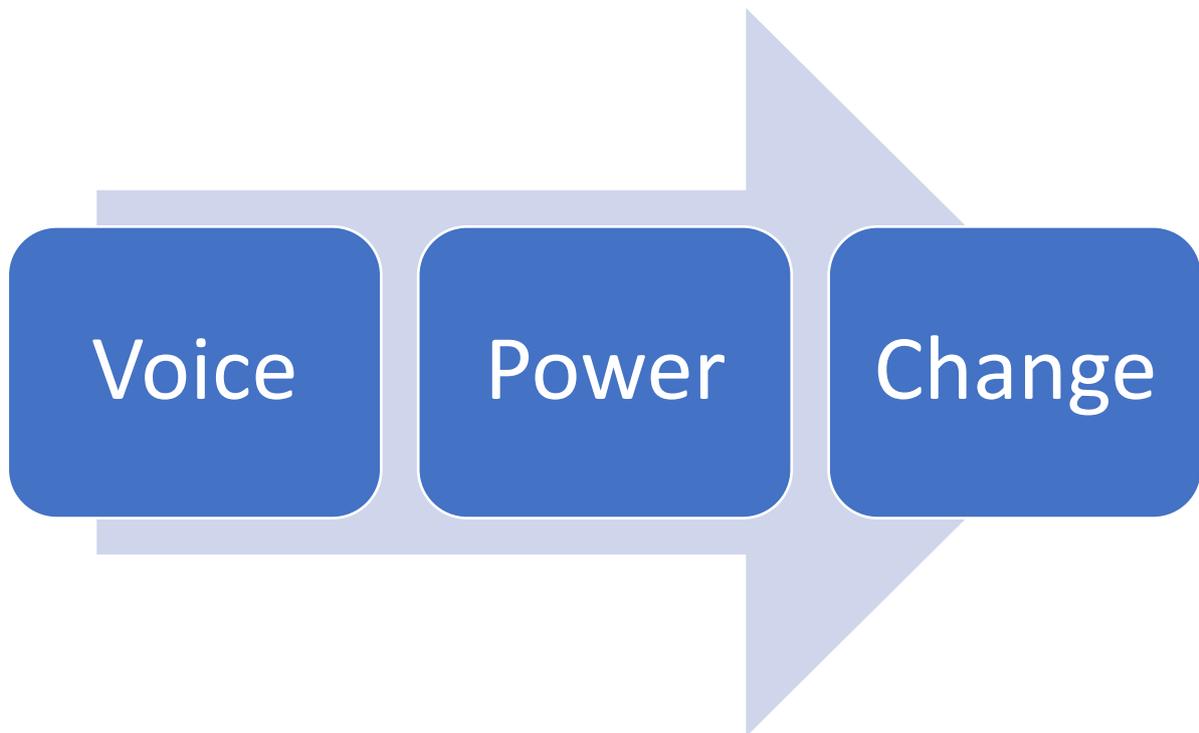


# Disability advocacy research in Europe: emerging fieldwork

Year 3 Research Report (summaries)



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## Contents

This Research Report is provided by the Research Committee to spotlight the emerging findings of 13 Early Stage Researchers (ESRs) employed on the Marie Skłodowska Curie Research Training Network on Disability Advocacy Research in Europe (DARE).

The DARE Project is co-ordinated by the Centre for Disability Law and Policy at the National University of Ireland, Galway, with the collaboration of partner institutions: the Institute for Social and Political Sciences (Portugal), Maastricht University (Netherlands), University of Leeds (UK), the European Disability Forum, the European Association of Service providers for Persons with Disabilities, the University of Iceland and Swiss Paraplegic Research.

The ESRs were invited to submit short working papers based on any aspect of their individual research projects during the third year. These chapters are based on emerging findings and insights, from desk based or fieldwork research (and building on summary findings presented at the joint training event in May 2022, as outlined in summary research report D3.4).

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# 1 Pathologisation of disabled childhood as an impediment for independent living

**Rados Keravica, Centre for Disability Studies, University of Leeds**

## Abstract

This paper draws from the ongoing qualitative doctoral research study on disabled children's participation in individual healthcare decision-making. It presents the emerging findings based on the set of in-depth semi-structured interviews with disabled children and their parents from England and Serbia. Parents of disabled children through the interactions with healthcare systems tend to become socialised into thinking of disability as an individual problem which needs to be cured. The decisions to pursue medical interventions imbued by the uncertainty of outcomes may be based on parents' and healthcare professionals' visions of the child's future and misconceptions of the disabled people's quality of life and the notion of independence. Adults' perceptions of disabled children's best interests leave little space for the meaningful participation of disabled children in decisions about their healthcare. A disregard for disabled children's participation may impede the gradual evolvement of their capacities and may result in internalisation of ableist attitudes.

Keywords: Child participation; Disabled children; Healthcare; Evolving capacities.

## Introduction

Disabled children face a greater likelihood than their non-disabled children to seek medical attention, including both general and specialized healthcare services and spend substantial time in hospitals and rehabilitation programs (Bricher and Darbyshire, 2005; Kuper et al., 2014). Due to perceptions of impairments as a problem, disruptive to a child's development, disabled childhood is marked by various forms of remedial treatments, therapies or surgeries which seek to restore bodily functions or ameliorate the impairment effects (Priestley et al., 1999; McLaughlin and Coleman-Fountain, 2014; McLaughlin, 2017).

The social model of disability as a 'big idea' of the disability movement underpins both disability studies and independent living philosophy (Oliver and Barnes, 2012). It focuses on the analysis of disabling environment locating squarely the problem in a society and its treatment of people with impairments. While the social model thinkers never denied that medical interventions may be useful to stabilise initial conditions (Oliver, 1996, p.36), there is a general tension concerning the idea of using the power of medicine to 'fix' the impairment. Oliver contends that 'many disabled people experience much medical intervention as, at best, inappropriate, and, at worst, oppressive' (Oliver, 1996, p.36).

In my research, I have decided to focus on elective impairment-related paediatric orthopaedic surgeries in relation to which I am investigating disabled children's participation. This focus allowed me to recruit children with a range of different impairments who experienced such treatments. The literal meaning of 'orthopaedics' in Greek is 'child correction' or 'straight child' which illustrates the extent to which such treatments are imbued by the ideology of normality (Shakespeare and Watson, 1998).

In this paper I present the emerging findings of part of the qualitative study which involved disabled children and young people and their parents from England and Serbia as they relate to the meaning of disability that families develop through encounters with healthcare

professionals and the implications of these meanings for disabled children's participation in decisions about their healthcare.

## **Methodology**

This paper draws on the ongoing research on disabled children's participation in healthcare decision-making. The research utilised qualitative social inquiry to elicit the views and experiences of disabled children and their parents on children's involvement in decisions about elective orthopaedic surgeries in England and Serbia. In total, 15 in-depth semi-structured interviews were conducted online with disabled children and young people aged between 10 and 22 (7 children from England and 8 from Serbia) and 16 interviews with parents (8 from England and 8 from Serbia).

The voices of disabled children and young people were central in this research and they were complemented by the views of significant others in their life – their parents. This approach is known as 'distributed methodology' and acknowledges the relationality of children's experiences (Mallett, 2014).

The findings presented in this paper refer only to selected themes that bear relevance to how the understanding of disability is construed by parents and children and how that understanding is shaped through encounters with healthcare professionals.

## **Findings**

The decisions to pursue certain impairment-related medical interventions may have unintended consequences. The power of medicine by establishing the hegemony of normalcy and pathologising all conditions that deviate from the standards of typical development may instil in parents and children the understanding of impairment as abnormal (Cooper, 2013). Thus, the decision to opt for medical intervention may result from a desire to get as close as possible to an ideal of normalcy (McLaughlin, 2017). Watson and Shakespeare warn that exposure to frequent hospitalisation and corrective treatments may lead to internalised oppression in children and the development of feelings of self-hate (1998, p.20).

I consider impairment-related orthopaedic surgery as a material-discursive practice imbued by ethical dilemmas and the values and meanings people attach to disability and life with an impairment. The findings I present in this paper draw exactly on those parts of conversations with disabled children and young people and their parents that revolved around their understandings of disability and the motivations that led them to opt for medical interventions.

### *Understanding of independence*

When discussing the motivations of parents and young people that led them to agree on the proposed medical interventions they were telling about hoped-for benefits. These discussions revolved around participants' perceptions of the quality of life of disabled people. Parents wanted to provide for their children the best future possible and they placed a high value on independence in adult life. However, their understanding of what independence means largely revolved around physical capacity and self-sufficiency. A mother of an 11-year-old boy with cerebral palsy from England, when I asked her about the outcomes that she is hoping that the surgeries would bring said:

Mother: A pain-free life? I mean, I can't imagine that anybody sitting in a wheelchair for the most, majority of the day is going to be pain-free. Nobody has said that to me. But I mean, I can't imagine. I want him to be as fit and healthy and active as he can be.

Another mother of an 18-year-old young woman with cerebral palsy from Serbia told about the attitude of a doctor who felt the urge to do anything possible to prevent her daughter from becoming a wheelchair user. This urge to do something about the young woman's impairment led to multiple surgeries, some of which actually resulted in decreased functionality of her body. A mother shared the following:

Mother: The doctor absolutely does not like to see children in wheelchairs. She [doctor] always emphasizes it. If a child can, if a child tries hard, she would prefer to prolong it as much as possible, the involvement of the wheelchair, because then a child is static and then there's no progress.... She's always insisted saying that her [daughter] did not need a wheelchair, yet. She doesn't like to see children in a wheelchair, hence she'd been trying on her [daughter] everything that's possible...

These narratives of parents reveal the beliefs and misconceptions related to the quality of life of disabled people including those using assistive technologies and other sources of support. The independence in terms of self-sufficiency was ranked highly among the hoped-for benefits of the surgeries. This is consistent with the findings of McLaughlin (2017, p.247) who also reported that medical interventions were seen as something that could provide greater independence. Understanding of independence as self-sufficiency differs starkly from the meaning of independence promoted by the independent living movement which emphasizes interdependence and choice and control over the support that a person receives rather than self-sufficiency (Mladenov, 2021).

#### *Disavowal of disability identity*

Oliver (1996, p.5) claimed that disability identity is constituted of three core elements: the presence of impairment, the experience of socially imposed barriers and self-identification as a disabled person. Watson (2002) questions the existence of disability identity as something stable and decontextualised. His study reveals a multiplicity of disabled young people's constructions of their sense of self. Many of them reject disability as identity through actions and narratives that help them to blend into the non-disabled category and minimize their differences.

This results from an understanding of disability as an inferior state of being and a demeaning label. The data from my study suggests that medicine plays a role in constructing the narratives of disability as an individual problem which is best resolved through medical interventions.

A mother of a 13-year-old disabled boy shared her experience of learning about her son's impairment:

Mother: And basically apart from the skeletal problems, he was a normal, healthy, functioning child. It's just his skeleton that is wrong. And as he [referring to a doctor] said to us, you know, he's a healthy baby, he's just got mechanical problems... And to have somebody say, actually, you know what, your baby is healthy. He's just got mechanical problems, is such a helpful mindset to get into, that you don't have an ill child.

Researcher: So that's framed as something that can be sorted out?

Mother: Yeah, and I think that's the thing, isn't it? He's just got mechanical problems...It sort of reassures you that they're not ill.

This initial construction of an impairment as a 'mechanical problem' formed a core part of the strategy that these parents used later to talk with their son about his condition:

Mother: And then when we had him, I think one of the things with him was, you know, we've never sort of mentioned the disabled word with him. We just said, you know, you're just different. And I think that's one of the problems that, you know, with labelling, that people do like to label people. And you know, we're all individuals and you can't, you can't make a sweeping comment. So I think I sort of pulled all that into play with him. And I wanted him to feel normal. I wanted him to feel like his friends. I wanted him to know that, you know, he was the same as everybody else.

It is evident from this example that these parents associated disability with severe illness and devalued state of being. That their son's impairment is a 'mechanical problem' which might be sorted out through medical interventions gave them hope and helped them to distance themselves from the category of disabled. Even though the multiple surgeries their son experienced did not eradicate his impairment, they invested efforts to help their son not identify as disabled with an aim to blend in more easily into the category of non-disabled and not think of himself as less valuable.

A 12-year-old disabled girl from Serbia was talking about the conversation between her mother and a doctor that went on in front of her:

Well, I heard him [a doctor] and my mom talking and he said that simply it can not be done for me, that simply, like...like I am a hopeless case, something like that.

In this case, a doctor when explaining to the mother that the surgery would not bring any benefits objectified this young girl referring to her only in terms of her impairment which is beyond repair in his view. Such objectification affects children's sense of self, diminishes their confidence or even leads to internalised ableism as internationalisation may begin at early age spurred by the messages about themselves that young people receive from others (Smith and Traustadóttir, 2015).

### *Pursuit of normality*

Most of the parents and disabled young people were able to pinpoint tangible benefits and improvements in the quality of life that resulted from the surgeries they had. Some of the examples of alleviated impairment effects included improvements in the child's gait and posture, reduced spasticity, alleviated pain, improved ability to stand or walk independently or at least with the support of mobility aids and to participate more effectively in favourite activities.

In some cases, the motivations to pursue surgical treatments stemmed not only from considerations of quality of life and alleviated impairment effects but from a desire to get closer to an ideal of normalcy. The idea of normalcy was so seductive that in some cases families pursued treatments which contained high risks and were imbued by a lot of uncertainties in terms of outcomes. Young people placed a high value on the esthetics of their bodies and favoured surgeries that helped to pass as normal.

An 18-year-old young disabled man from Serbia with cerebral palsy talked about the reasons why he thought of surgery as a good option for him:

Well, I was hoping that I could work normally as I'm walking now more or less. I mean, people almost can't tell the difference between me and others so I am totally happy. Although that's the least of my problems, whether people can notice the difference or not, what's important for me is that I can move without pain and go swimming without any difficulties so I'm perfectly satisfied with the surgery.

Another disabled boy with cerebral palsy from Serbia who is 17 shared his experiences of being stigmatized and labelled by his peers throughout his adolescence. The social stigma he experienced led him to develop feelings of shame:

Surely, I'd love to walk like everyone else and all of that. It's not easy for me in some situations, and honestly, sometimes I don't like to see myself in the mirror. But ok, that feeling passes quickly. I am aware that I have to fight and that at the end of the day, I don't have any other choice.

The surgery represented a form of work on the body that young people undertake to minimize their difference (McLaughlin and Coleman-Fountain, 2014; McLaughlin, 2017). Those whose impairments were such to allow them to get really close to an ideal of normalcy thanks to surgery appreciated the possibility of passing as 'normal'. That had an effect on distancing further from the category of disabled as they considered themselves different from 'really' disabled people with more severe impairments.

#### *Dis/empowering children in encounters with healthcare professionals*

A domain of healthcare is particularly sensitive and the one in which the tension between child protection and support for their increasing levels of autonomy comes up to the surface most bluntly.

Due to adults' uneasiness related to children's impairments and their desire to enable their children as best future possible, the decisions to pursue medical cures seem to leave little space to be questioned. However, that should not mean that children should not be given the chance to engage in a dialogue with adults, pose questions and get access to all the information they might need to develop an understanding of what will happen to them. As we can see from the following examples, it happens often that children are sidelined in medical encounters and that they do not have enough chance to express their views and concerns. The 18-year old young disabled woman from Serbia said:

...I think that they [healthcare professionals] should ask a child directly, and not that I have to tell to my mum, and then my mom to ask them, because it has been happening quite often that I had some questions and then I had to tell to my mom: 'Mom, please ask this', because my views did not matter much.

In the following example the 17-year-old young man from Serbia explained how he felt after being examined by a doctor who did not pay sufficient attention to his concerns:

In most of the cases, he [a doctor] ignored me, like he basically had conversations with my mother and father only, and he completely ignored me, so... I was just there like some sort of object for trying out...I don't know...his new ideas.

The role of the parents in medical encounters proved to be significant for how children are going to be treated by healthcare professionals. Parents may act as a barrier to children's participation or a source of support. If the parents considered their child's participation important, they encouraged them to ask questions or insisted that healthcare professionals explain to them what is at stake. Thus, the positioning of children in a three-way relationship of parent-child-healthcare professionals strongly depended on adults' perceptions of the child's competence and maturity and the importance adults attach to the child's participation.

A 16-year-old disabled girl from England shared a positive experience of being involved in the process of making a decision on the proposed treatment. Her parents deemed it important to help her retain a sense of choice and control over what is going to happen to her:

Well, my parents kind of sat me down a few days later, and explained to me what would happen and answered if I'd like the consequences if I didn't have it, like the pain will get worse. And I would not be able to walk. And they told me exactly what would happen. And the risks, and they just told me everything about it really. And they said it's up to me. It's my decision. So they kind of left it up to me to decide but made sure they were there for me.

This example shows that the experiences of medical treatments are not something in which children prefer to be positioned as passive spectators and objects of adults' concerns. They want to be engaged and have their say in what is happening to them. Children's capacities evolve through experience and need to be understood relationally, constructed through intergenerational relations with adults (Lansdown, 2005).

## Discussion

Brisenden (1986) in his writing on the negative implications of the medical model of disability for independent living of disabled people warns against the cases when medical treatments and hospitalisations are recommended for the disabled even when those do not necessarily lead to improvements in quality of life. According to him, frequent hospitalisations and medical interventions represent a source of disablement. He explains that this is a consequence of how medicine views and defines disability:

This has occurred due to a failure of imagination, the result of the medical profession's participation in the construction of a definition of disability which is partial and limited. This definition has portrayed disability as almost entirely a medical problem, and it has led to a situation where doctors and others are trapped in their responses by a definition of their own making. (Brisenden, 1986, p.176)

Without intention to downplay the benefits of the orthopaedic surgeries that children experienced, I want to highlight the risks associated with a pursuit of a medical 'fix' that bears relevance to children's potential for independent living.

This risk is embodied in at least four different ways. First, the power of medicine constructs the meaning of independence in terms of self-sufficiency and sets the goals of impairment-related medical interventions in terms of independent functioning. Mladenov (2021, p.10) when writing about the independent living movement's struggle for the meaning of independence as choice and control over the support one receives and interdependence with others rather than self-sufficiency explains that 'powerful disability policy actors have

perpetuated a one-sided interpretation of independence as self-sufficiency, interpretation whose reproduction has constituted a hermeneutical injustice inflicted on disabled people’.

Second, prompted by the power of medicine, both children and parents develop an understanding of disability as an individual problem which is best resolved through medical interventions. Disabled childhood is often the site of medical interventions. Young people derive their sense of self from others and gain their first knowledge about disability through narratives of medicine. Griffiths (2018) in his research on disabled young people’s involvement in disability activism showed that the social model of disability as a ‘big idea’ of the disability movement remains distant to young people not least because of the narratives constructed by medicine and preoccupation with fixing the impairment in the childhood.

Third, the pursuit of normality through risky medical interventions imbued by uncertainty which goes beyond stabilisation of initial conditions and alleviation of impairment effects casts disabled people as ‘abnormal’. It further leads disabled young people to distance themselves from other disabled people. In the absence of positive role models and peer support, these ideas may seem remote to young disabled people.

Finally, the parenting practices which support children to express their views and have their say in important decisions nurture children’s evolving capacities and increase their potential for independent living in adulthood. If children develop the habit of being asked for opinions they might learn that their opinions matter and are likely to grow up in self-determined individuals.

## Conclusion

Testimonies of young people and their parents reveal that there are unintended consequences of frequent hospitalizations and exposure to medical interventions. In the pursuit of medical ‘fix’ disabled children and their parents develop an understanding of disability which correspond to the individual model of disability and may lead to repudiation of disability identity. The ideas of the social model of disability and disability pride which are central to the independent living movement may be remote for them. Disabled children, both in Serbia and England seem to be rarely consulted on decisions about their healthcare in a meaningful manner. Adults’ preoccupation with children’s impairments leaves little space for children to take part in the discussions on their best interests and quality of life. Ignoring children’s views on these important matters downplays the importance of nurturing their increasing maturity and autonomy.

If disabled children are to grow up to be adults in a position to retain choice and control in their lives then their evolving capacities need to be recognised and nurtured today by the people involved in their care.

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## 2 The role of Rights Protection Officers in enabling effective access to justice for disabled women in Iceland

**Eliona Gjeczaj, Centre for Disability Studies, University of Iceland**

### **Abstract:**

Limited research has focused on access to justice for disabled women who have been subject to violence. There is limited knowledge and understanding about the reporting and prosecution of violence against disabled women internationally and in Iceland, where the research reported here is carried out. Using an interdisciplinary human rights approach, this article focusses on the role of Rights Protection Officers as a procedural accommodation in enabling effective access to justice for disabled women when detecting, reporting and prosecuting the gender-based violence that they were subjected to. It draws from qualitative interview data with disabled women, professionals working within the justice system, and experts in the disability field and justice system. It furthermore draws on human rights law and Icelandic legislation and criminal procedures, to analyze the importance of such role in supporting women their right to access the justice. The findings describe and discuss the role of Rights Protection Officers regarding access to justice for disabled women, including the limitations to their role.

**Key Words:** Procedural accommodation, access to Justice, rights protection officers, disabled women, violence, Iceland

### **Introduction**

Disabled women have already been shown to be at higher risk of experiencing violence than non-disabled women (Hughes et al., 2012; Krnjacki, et al, 2016; UNFPA, 2018). Despite this, limited research has focused on access to justice for disabled women who have been subject to gender-based violence internationally and in Iceland, where this study is based. This paper aims to provide an understanding, contribute, and expand the knowledge regarding access to justice for disabled women subjected to violence.

General Comment No.3 on article 6 of the UN Convention on the Rights of Persons with Disability (CRPD) discusses how women with disabilities face various barriers to accessing justice, including dismissive attitudes, negative stereotypes, lack of accommodation, problematic reporting procedures, which discourage seeking legal redress (GC3 on art.6 2016, para 52). As part of enabling access to justice, Article 13 of CRPD, which Iceland has ratified, requests that states ensure effective access to justice for persons with disabilities on an equal basis with others through the provision of procedural and age-appropriate accommodations and facilitate their effective role as direct and indirect participants in all stages of legal proceedings (para 1). Although not labeled as such, the provision of the Rights Protection Officers (hereinafter RPOs) could be considered a group-oriented procedural accommodation to assist with the protection of rights of disabled people. The RPOs are public officials who work in the Right's Protection Agency of Ministry of Social Affairs and Labour. They have expertise in the disability field and their provision forms part of the Act on the Protection of the Rights of Disabled Persons (2011) and is a recommendation under the State Prosecutor's Guidelines of 2018 regarding sexual offences cases involving disabled people.

This paper focusses on the role and involvement of the RPOs in supporting disabled women in safeguarding their rights. It draws from interview data collected, human rights law and

Icelandic legislation, to analyze and understand the importance of RPO's role to protect the rights of disabled women when reporting and prosecuting violence. The paper begins by setting out the overall research context and methodology. It continues with a brief outline of the human rights approach to disability, which encompasses the right of disabled women to live free from violence, and to prosecute the violence they experience. Relevant Icelandic legislation and State Prosecutor's Guidelines will then be discussed. Finally, it will provide a description of, and discussion of emerging findings on RPO's role and function, and how important they are in enabling effective access to justice for disabled women when defending and accessing their rights. This includes highlighting RPO's helpful role in the overall proceedings in informing other justice workers in how to facilitate and accommodate disabled women who report violence. Brief comments on the limitations of RPO's roles will conclude the paper.

### **Research context and methodology**

The research reported here is part of an ongoing study focusing on the access to justice for disabled women who have been subjected to gender-based violence in Iceland. It aims to gain in-depth knowledge through exploring the lived experiences of disabled women as well as those supporting them through detection, reporting and prosecuting violence. The research is interdisciplinary, it takes a human rights approach and combines disability and gender studies. The human rights approach is both driven and supported by the CRPD (Quinn & O'Mahony, 2017), and recognizes disabled people as rights holders (Kanter, 2015). This research focuses on the actualization of CRPD's right to freedom from violence (Art.16) and access to justice (Art.13) for disabled women (Art.6) and the analysis of the interlinking between these three Articles and of how the right to access to justice and to be free from violence stated by them have materialized in the lives of disabled women in Iceland. The interlinking of these rights will be briefly discussed in the next section.

This paper draws from the qualitative data collected regarding the role of RPOs and their involvement in supporting disabled women in effectively accessing the justice system: six semi-structured interviews with RPOs, and document analysis of applicable Icelandic legislation and guidelines, and international human rights treaties. These interviews were with five participants between September 2020 and June 2021. One RPO was interviewed twice. In addition, information is drawn from other interviews with disabled women, professionals working within the justice system in the reporting/prosecuting structures (e.g. lawyers, police, prosecutors, and judges), and experts in the disability field and justice system, as complimentary regarding RPO's role in supporting disabled women to access the Icelandic justice system. Grounded theory approach has been used to guide the analysis of the data (Charmaz, 2014; Padgett, 2017). The content of these interviews provided the data for this article. Some of the Icelandic legislation and other written materials for analysis, have been translated to English. All the documents used are drawn from the English translation.

### **CRPD and Icelandic law**

Iceland signed the CRPD in 2007 and ratified it in 2016. It now waits for the implementation of its rights and requirements. Addressing gender-based violence against disabled women means that states need to pay particular attention to the gender and disability-specific measures required by Article 6 on women and girls with disabilities, Article 16 to ensure their full enjoyment of the right to be free from violence, and article 13 on the right to access the justice system to report and or prosecute violence they have been subjected to. Paragraph 5 of Article 16 targets the same obligations as in Article 13: urging states to adopt legislation and policies

which ensure that disabled women get the adequate support needed to detect violence, and that their reports are taken seriously. More specifically, paragraph 1 of Article 13 requests that states ensure effective access to justice for persons with disabilities on an equal basis with others through the provision of procedural and age-appropriate accommodations and facilitate their effective role as direct and indirect participants in all stages of legal proceedings (CRPD 2006, Art. 13(1)). Despite all of these requirements, Iceland, like many other states, still struggles to provide measures and legislation to prevent and/or properly prosecute violence against disabled women in particular, and in providing an effective access to justice. However, even though it is not listed as a procedural accommodation, there is an Icelandic law which permits as a procedural accommodation the provision of RPOs to assist with the protection of rights to disabled people, especially in cases of rights-based violations.

***Act on the Protection of the Rights of Disabled Persons, No. 88/2011 (RP act)***

The purpose of this act is to ensure the protection of rights of disabled people and that disabled people have adequate support in safeguarding their rights, and in doing so, the CRPD is to be taken into account (art.1). This act came into force immediately and provides for three types of protection of rights. The provision of RPOs being one. The RPOs are public officials with knowledge and expertise on the disability field, and thus, are ideally placed to assist a disabled person in defending and accessing their rights such as living free from violence and to detect and prosecute it.

The act sets out provisions on regional RPOs who, in their respective areas, have the task of monitoring the situation of disabled people and assisting them in all matters concerning their services, personal finances and rights issues in general (art 4-5). Article 6 states that: anyone witnessing, hearing, or being told about an incident of right infringements of disabled people must report it to the RPOs and or to the police. This would include everyone living in Iceland e.g., partners, spokesmen, family, and staff at services. When informed of a violation of the disabled person's rights, the RPO will provide the victim with support in seeking redress (art.6). In cases of violence, the RPO following the announcement will support the disabled person to pursue further actions, such as report violence to the police or protect their rights in court.

***State Prosecutor's Guidelines***

The Icelandic State Prosecutor issued in 2018 guidelines on the handling of sexual offense cases involving disabled people, to the police and prosecutors to ensure equality in access to the judicial system and procedures. Involving the RPOs from the early stages is among the recommended guidelines. This can be understood as a recommended procedural accommodation to all disabled people. However, as these guidelines are not legally binding, it must be highlighted that it is up to police, prosecutors, and judges to issue or refuse the provision of the recommended guideline on involving an RPO in a given case. Furthermore, these guidelines are only for cases involving sexual violence.

**Emerging findings.**

The legal obligation on everyone living in Iceland under the RP Act 2011 to report violation of disabled people's rights to RPOs, means that the RPOs play a key role in supporting disabled people to protect their rights, report violence and access the justice system. The RPOs role and function is described by the RPOs as falling under CRPD's articles 12 on Legal Capacity and 13 on Access to Justice, which position the RPO by the disabled person in supporting them regarding supports and services and being equal before the law (Art.12) as well as supporting

them when accessing the justice system and securing supportive services after or before that (Art. 13), while respecting the will and preference of the individual. One RPO stated:

First of all, as a rights protection officer, my key role is supporting disabled people according to the 12<sup>th</sup> and 13<sup>th</sup> articles of the UN CRPD ... in the 13<sup>th</sup> article we have had the role to help people in the judicial system, and to go through for example police interrogation ... and when people go to court, to support them in having a say in the matter ... so they have more equal access to the system than they did before.

### *Start of process*

Although the RPOs state that they don't have a strict procedure, it can be argued that there is a flexible structure on how they deal with cases: a) receive a notice or call about the case; b) obtain consent from the disabled woman to work with them on the case; and c) choose the follow-up actions depending on what the disabled woman wants to do with her case. The reporting process could start when the disabled individual, family, police or anyone contacting the RPOs. RPOs can also initiate cases if they hear or see violations of rights. The police also often call the RPOs in cases of violence in order for the RPOs to support the disabled individual and to gather information on the disabled person and their need of accommodations and supports. Regarding how the reporting process starts, a RPO explained:

The process usually starts with the person or the police. For example in the case of violence the police contacts us and asks us to be a part of the interrogation, or the investigation of the matter, to support the individual in the interview that they take, to evaluate and to provide knowledge about the individual, so they can receive the right support.

Such advanced preparation is key in facilitating and enabling the disabled person to give a statement while having adequate support and assistance. This highlights the role of RPOs in informing the police and requesting reasonable accommodations to meet the needs of the disabled woman. But before taking any actions, the RPO must obtain consent to be involved in the case from the disabled woman.

### *Consent*

The importance of obtaining consent from the disabled individual to be involved in the case is emphasized by the RPOs as a key step in supporting the disabled person and as a major part of their role. The RPOs stressed the need to have the consent from the violated person and not just from other people. One RPO said:

She [the woman who was violated] told her father and mother about this and they ... they came to me and asked for help. And I told them ... of course ... we shall talk... always talk to the one who is disabled. Rights Protection Officers, they cannot do anything unless the one who is disabled agrees.

In cases where the police call the RPOs, the RPO start seeking consent by explaining to the disabled person who they are and their role, explaining that the person has the option to have a female RPO, or not having an RPO involved at all, as well as the type of supports the RPO could assist them with.

### *The various ways RPOs work*

The RPOs constantly referred to and repeated the fact that they use different ways to accommodate the person that seeks their help depending on what the person wants the case to go to. They stated that follow-up actions can take many shapes and forms, but it is always up to the disabled women to decide the direction of the case. Regarding this, one RPO explained:

It depends what the person wants, maybe it goes straight to the police, maybe to counselling, maybe to the social services if you want to change your house or get some kind of help from them... and maybe it'll go to Bjarkarhlid [Family Justice Center for survivors of violence], it depends on the person ... it's their choice what to do.

This highlights the different actions RPOs take to support the individual in seeking justice and the support services outside of the justice system but relevant to the suffered violence. Regardless of how a case went to police, the communication between RPOs and police involves exchanging and gathering information on the disabled person and their need for accommodations and supports in preparation for the police statement. A RPO explained:

At the police ... when they are investigating the case then it's our job to make sure that the police does things in the way that is ... right for the person. And that can be: maybe not going down to the police station, if you are afraid of the police, ask them not to wear police uniform, we can be at my office, we can come to your house, we can, you can choose what's best for you. ... We take into account like...if people are autistic: what's the lighting like, what's the sound like ... to make everything as easy as it can be for the person, judging case by case.

Thus, in addition to supporting the disabled woman to report and while giving the police statement, the RPOs inform, advice, and request the needed reasonable accommodations to be provided by the police. In other words, RPOs are advisors for the police in how to approach the person and their needs, and as an observer of the interaction to point out how or what things or ways should be used or not when interacting with a disabled person. The RPOs listed a number of different reasonable accommodations requested and provided depending on the case: use different communication devices, sign language interpreters, take the interview at people's homes or the RPO's office, and police changing into casual clothes. In cases involving disabled foreigners, interpreters from abroad have been used to accommodate the privacy of the disabled woman, and support the disabled women through them.

Moreover, RPOs also play an important role in requesting procedural and reasonable accommodations before and in court depending on the needs of the disabled woman. Examples included meeting with the disabled woman and her lawyer before court to explain her rights, provide pictures of all involved, visiting the court room before the hearing and explaining where she, the judge, the lawyer and RPO will be sitting, removal of perpetrator from the courtroom during her statement and extra time to think and answer questions during the court hearing.

One of the RPOs described how she prepared a disabled woman before she appeared in court:

I have been in court with this one woman and I could be with her side, beside her, umm so yeah. I also prepared her before. We went to the court before, I showed her around, I got permission to show her the place before she went there. So, here you will sit and I will sit here and the judges are there.

Regarding requesting permission to show the courtroom to the disabled woman, One RPO highlighted that ‘the lawyer does that, but I asked her to do it’. Hence, similar to informing and advising the police in how to interact and what to provide to the disabled women during the police statement, the RPOs do the same with judges, prosecutors and lawyers. The RPO stated:

So I knew that she does long pauses when she talks ... she needs time and I knew that so I could you know, I could deliver that information to the police and to the lawyer ... before the hearing, I told the judge and you know the attorneys that she will have her time to answer and she needed time to think to answer, that doesn’t mean that she is not going to and so we have to you know give her time, so we had to be like be really sure that she has said anything she wanted.

All of these accommodations stand as proof to the importance of the role of RPO to seek and provide them. As outlined in Article 13 of CRPD, the provision of procedural and reasonable accommodation is vital for disabled people to access their rights, in this context to report and prosecute violence. Thus, the role of RPOs is vital in enabling effective access to justice for disabled women, in requesting accommodations throughout the process of reporting and prosecuting violence, and in informing and advising justice workers why and how these accommodations need to be provided.

#### *RPO limitations*

The involvement of RPOs in cases being only a prosecution guideline means its provision depends on individual police and judges, as stated by a RPO: ‘it is very different between you know police officers if our role is accepted or not in this situation’ and ‘the lawyer had to ask the judge if it was ok for [RPO] to be present in the courtroom because that’s not like a part of the law to do that’. One RPO disappointedly expressed that despite the existence of the prosecution guidelines, it still depends on the individual police officer to respect the rights of disabled people: ‘I know it really comes down to the individual police officer, you know, if they have this ... this basic level of respect for the dignity of, of the person they are interviewing or not,’. Thus, the provision of RPOs should be legitimized as part of enabling effective access to justice for disabled people/women and not depend on individual justice workers to provide reasonable accommodations or not.

Furthermore, while highlighting the changes over the years, all RPOs stressed the need for their role to be strengthened and given more authority, one of them said: ‘there’s more authority needed, yes, to the rights protection officers yes’. As evident, the support provided by RPOs to disabled women throughout accessing the justice system highlights how crucial their involvement is in effectively accessing justice. However, their role needs to be strengthened and more authority be given.

#### **Conclusion**

This paper has analyzed and highlighted the important role of Rights Protection Officers as a procedural accommodation in enabling effective access to justice for disabled women who have been subjected to gender-based violence in Iceland. The RPOs role is crucial to protect the rights of disabled women when reporting and/or prosecuting violence. Their help in seeking supports and reasonable accommodations to meet the needs of the disabled woman is essential. In addition, they play a key role in informing other justice workers in how to facilitate and

accommodate disabled women who report violence. Hens, the provision of RPO should be legitimized as part of enabling effective access to justice for disabled women and their role be strengthened.

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### 3 Exploring the Interface Between Dementia, Autonomy and Residential Aged Care in Ireland

**Ainsley K McLean**

#### **Abstract**

Autonomy is a central tenet of moral, political, and legal philosophy. In a more practical sense, the right to make individual choices and actively participate in the decision-making of one's care is a fundamental principle of autonomy. This chapter explores the interface between autonomous decision-making in residential aged care for older persons living with dementia-related to daily care in these settings.

Drawing on the scholarship of disability human rights, the concept of autonomy focuses on a rights-based approach instead of the more traditional scholarship that focuses on the theoretical underpinnings of philosophy and moral thought. This chapter offers unique insights into how everyday decisions are made around care and manifested through an autonomous lens. This chapter identifies how autonomous decision-making in residential aged care settings can be supported and developed for persons living with dementia in both a practical and conceptual manner.

**Keywords:** Autonomy, Dementia, Decision-Making, Disability, Residential Aged Care

#### **Introduction**

Autonomy is a central tenet of moral, political and legal philosophy. In a practical sense, personal autonomy, on which this chapter is focused is the 'ability of an individual to direct how they live on a day-to-day basis according to personal values, beliefs, will and preferences.'<sup>1</sup> Autonomous living is about respecting a person's dignity, privacy and self-determination. In health and social care, this involves the person who uses services making informed decisions about the care, support, or treatment they receive.<sup>2</sup>

This chapter aims to identify how autonomous decision-making in residential aged care settings can best be supported and developed for persons living with dementia. This chapter focuses on the interface between dementia, autonomy and decision-making in residential care at the conceptual level, rather than in-depth analysis.

First, I will begin by providing a contextual background of what dementia is and how this can be viewed through a disability rights-based lens. This will serve as the backdrop of the chapter.

Secondly, I will explore the concepts of autonomy as it applies to persons living with dementia in residential aged care settings. I will practically highlight how a person might be restricted or denied their autonomous decision-making in daily life in care.

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<sup>1</sup> HIQA, 2016

<sup>2</sup> HIQA, 2016

Thirdly, I will highlight fundamental principles of autonomous decision-making around care can be further realised by applying these principles.

### **Dementia Through a Disability Lens**

This section will provide the backdrop to the chapter. Doing so will contextualise dementia through a disability, rights-based lens. Subsequent sections of this chapter will build on these concepts.

#### ***Dementia***

The World Health Organisation (WHO) defines dementia as:

"An umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain activities of daily living"<sup>3</sup> People with dementia experience many issues such as difficulty getting a diagnosis, lack of awareness, the stigma around dementia, the denial of rights, autonomy and decision making choices<sup>4</sup> Dementia is often described in the literature as 'chronic and insidious in nature, where there is a "disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement."<sup>5</sup>

The most common form of dementia is Alzheimer's disease, estimated between 60-70% of cases. Other forms include vascular dementia, dementia with Lewy bodies and frontotemporal dementia<sup>6</sup> While the chances of developing dementia are strongly correlated with age, it is not solely related to ageing, with some people developing young-onset dementia.<sup>7</sup>

In divergence and shift of tone, Alzheimer's Europe has long advocated that the experience of dementia cannot merely be prescribed as a set of symptoms, where "cognitive decline and incapacity become the central focus".<sup>8</sup>

#### ***Understanding Dementia through a disability lens***

Dementia is a significant cause of disability among people over 65 years of age, and the prevalence is rising.<sup>9</sup> The World Health Organisation (WHO) has identified dementia as one of the leading causes of disability and dependence in old age, with an estimate of currently 47.5

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<sup>3</sup> World Health Organisation (WHO) 2017 P 2

<sup>4</sup> WHO, 2017

<sup>5</sup> WHO, 2019

<sup>6</sup> Ibid P2

<sup>7</sup> Hennelly, N, 2020, p 2

<sup>8</sup> Gove et al, 2017

<sup>9</sup> Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 12, 459-509.

million persons living with dementia (PLWD), with a further 7.7 million new cases diagnosed every year.<sup>10</sup> The European Union (EU) faces significant demographic changes, with population ageing being a common challenge for the Member States in the medium to longer-term perspective.<sup>11</sup> Within the EU, public expenditure on long term care is projected to increase from 1.6% to 23.7% of GDP between 2016 and 2070.<sup>12</sup> Across the Irish landscape, approximately 19,000 people living with dementia are believed to be living in long-term care.<sup>13</sup>

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) gives voice, visibility and legitimacy to all persons living with a disability. They are meaningful rights holders under the CRPD committee clearly views people with dementia as part of its conceptualization of disability in Article 1 of the CPRD

In its innovation, the UNCRPD<sup>14</sup> counteracts an overly paternalistic medical model, where equality seeks to remedy these deficits by elevating the voice of all persons with disabilities, including persons living with dementia, through meaningful participation and inclusion. In its creation, the UNCRPD has been 'heralded as a new era for people with disabilities.'<sup>15</sup> Although the Convention does not define disability in an interpretative sense, it still provides a comprehensive reference in Article 1<sup>16</sup>

'Those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

The Convention is broad in scope, but there is little doubt that the cognitive and physical impairments caused by dementia are fully recognised as a disability. As articulated in Article 1 of the UNCRPD,<sup>17</sup> persons living with dementia are explicitly identified as intended beneficiaries of the Convention and bring with it the promise to 'ensure the full and equal

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<sup>10</sup> Alzheimer's Disease International and WHO. Dementia: a public health priority. Geneva: World Health Organization; 2012 ([http://www.who.int/mental\\_health/publications/dementia\\_report](http://www.who.int/mental_health/publications/dementia_report))

<sup>11</sup> Spasova, Slavina & Baeten, Rita & Coster, Stephanie & Ghailani, Dalila & Peña-Casas, Ramón & Vanhercke, Bart. (2018). Challenges in long-term care in Europe. A study of national policies. 10.2767/84573.

<sup>12</sup> European Commission (2018), The 2018 Ageing Report, Economic and budgetary projections for the 28 EU Member States (2016-2070) Directorate-General for Economic and Financial Affairs.

<sup>13</sup> O'Shea, E. Keogh, F. and A. Cooney (2019) The Continuum of Care for People with Dementia in Ireland. Tullamore: National Dementia Office.

<sup>14</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106,

<sup>15</sup> Lawson, A (2007) The United Nations Convention on the Rights of Persons with Disabilities: New era or false dawn? *Syracuse Journal of International Law and Commerce*, 34 (563).

<sup>16</sup> CRPD, Article 1.

<sup>17</sup>CRPD, Article 1.

enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.<sup>18</sup> This significant development elevates the voice of persons living with dementia as a whole person with an entire and meaningful life.<sup>19</sup> But it also reaffirms the rights of all persons living with dementia to determine their level of care and engagement in Society, to which active participation and inclusion can be fully recognised.

## Autonomy and Residential Aged Care

This section will explore the concepts of autonomy as it applies to persons living with dementia in residential aged care settings. It will practically highlight how a person might be restricted or denied their autonomous decision-making in daily life in care.

### *The Concept of Autonomy*

The concept of autonomy has its etymological roots in two Greek words, 'self' and 'rule or law' Thus, autonomy is self-rule.<sup>20</sup> Personal autonomy is a 'constitutive element of all rights.'<sup>21</sup> In essence, this means that every right has an autonomous component at the very heart of it.<sup>22</sup> In the normative sense, the autonomous element 'bestows the right-holder the freedom to choose whether, and under what circumstances, to assert the relevant rights against duty bearers.'<sup>23</sup>

This chapter does not advance a comprehensive jurisprudential account of the relationship between rights and autonomy, nor does it expand beyond the footings of philosophical insights or political thought. Instead, it chooses to focus on the decision-making aspect of autonomy for persons living with dementia in residential aged care facilities in Ireland.

By Raz,<sup>24</sup> autonomy has two crucial yet distinct aspects. The first is the primary aspect - this is where a person is genuinely autonomous when one chooses how to live their life according to their will and self-determined goals.<sup>25</sup> Next is the secondary aspect, where autonomy scrutinises what constitutes one's own will and preference. For example, in the context of care, a person may express their desire to spend time in the community garden of the nursing home – this is a self-determined goal with clear expression. Perhaps, autonomy is better understood through Doyle and Gough's<sup>26</sup> scholarship that speaks to two levels of autonomy; freedom of

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<sup>18</sup> CRPD, Article 1.

<sup>19</sup> Brooker, D. (2007). Person-centred dementia care: making services better. Jessica Kingsley: London

<sup>20</sup> Shawler et al (2001) in Lindley (1986)

Lindley, 1986 p5.

<sup>21</sup> Parchomovsky & Stein, 2021

<sup>22</sup> Ibid at 59

<sup>23</sup> Ibid at 59

<sup>24</sup> Raz (1986) 369-72

<sup>25</sup> Ibid at 144, 370-1

<sup>26</sup> Doyal, L & Gough (1991)

agency- freedom and choice to action. And secondly, critical autonomy, whereby the individual has the opportunity to express both freedoms of the agency.<sup>27</sup> If the latter is applied to the garden context, we know that a person has the freedom of agency to visit the garden through action.

In a practical sense, the person has the freedom to choose to visit the garden but is restricted and limited by environmental structures. For example, the garden can only be accessed with accompanying nursing staff or via access to critical pads on doors. This demonstrates how people are denied their freedom of agency and choice of action in practice.

### *Pseudo-Autonomy*

As the name suggests, pseudo autonomy is a spurious term used to describe decisions that appear autonomous but lack proper consultation with the person living with dementia in a nursing home.<sup>28</sup> Another term is what Boyle describes as 'minimally autonomous' this is where a person is required to possess the psychological capacity to formulate options and make informed choices. This criterion can be challenging to meet for people with dementia, especially when they are perceived to 'lack capacity' In contrast, a person can still be capable of making a decision or expressing preferences and consent in different ways. This could include non-verbal expression as a way to express their autonomy. The following scenario is only too common where a person is deemed to be exercising their freedom agency but has limits or restrictions to their autonomy as highlighted below;

*Mrs G is placed into a nursing home after a series of falls. Her clinicians and her family recommended that moving to a care home would be the most appropriate avenue given the lack of community supports currently available to her and the family. Mrs G initially agreed to the admission, but on the condition, that it was temporary and for convalescence only. It was later determined that Mrs G would need to reside in the nursing home on a more long-term basis, as questions about her capacity to make decisions about her everyday life were brought into question after receiving a diagnosis of moderate dementia. Mrs G did not agree to this being long-term and was capable of expressing her autonomous self throughout the entire process from admission to placement.*

Pseudo-autonomy is insidious, often masquerading under the guise of genuine autonomy. In the context of care, anecdotal evidence like Mrs G's situation only highlights further how pseudo-autonomy can manifest in practice because staff ascribe the decision to remain in the

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<sup>27</sup> Doyal & Gough (1991) in Boyle (2008) p 299.

<sup>28</sup> Ibid

nursing home long term, claiming it is a decision she autonomously made, when in fact her express will is the opposite.

### ***Residential Aged Care***

The growing practice of institutional care among older persons living with dementia is particularly evident as the ageing population expands globally.<sup>29</sup> In response to this expansion, nursing homes have become more widespread and embedded within the geographical, socio-political and legal landscapes of Irish Society. The proliferation of institutional care can affect all rights' most fundamental: inherent dignity, individual autonomy, and the right to liberty and freedom of movement.

For this chapter, residential aged care also refers to a nursing home, which is a congregated setting where older persons reside and receive care and assistance with their daily living. There is a scant body of knowledge in the Irish literature about whether and how consent to admission is obtained from residents in nursing homes. It is also not known whether and how consent to remain is revisited during the person's stay in nursing homes through formal processes and structures. Although a vast majority of persons living with dementia reside in their own homes and community, There are several reasons why a person living with dementia enters into residential aged care, and these include increasing care needs, lack of suitable community alternatives as well as a sense of 'burden' to family members and carers respectively<sup>30</sup>

Although the disability movement has identified that institutionalisation undermines the autonomy of disabled older people, it has also been recognised that constraints on autonomy are more prevalent in these settings<sup>31</sup>

### **Supporting Autonomous Decision-Making in Residential Aged Care for Persons with Dementia**

Having first highlighted how personal autonomy can be restricted, this section focuses on key principles which promote and support autonomous decision-making in care.

#### ***Autonomy: A fundamental right***

In the context of autonomous decision making and residential aged care, there is a growing body of literature to suggest that the perceived degree of involvement in everyday decisions within institutional settings is directly linked to a person's well-being<sup>32</sup> ; furthermore, autonomy is consistent with determining a person's quality of life within these settings<sup>33</sup>

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<sup>29</sup> Annear et al (2016) p. 753-756,

<sup>30</sup> Horsman Hogan, Florence (2022)

<sup>31</sup> Boyle (2008) p 303.

<sup>32</sup> Shawler, Rowles and High, 20001

<sup>33</sup> Van Theil & van Delden, 2001

Once a person is diagnosed with dementia, many may encounter injustice, inequality and marginalisation.<sup>34</sup> Cantley and Bowes state that discrimination, segregation and social exclusion can occur<sup>35</sup> primarily in the context of institutionalised care. It is further noted that personal autonomy can be further compromised.<sup>36</sup> This is especially true for opportunities to exercise choice and control in decisions around their care.<sup>37</sup>

In a shift of tone, this section of the chapter will briefly examine fundamental principles on development and support of autonomous decision-making. The promotion of autonomy is considered an essential aspect of person-centred dementia care<sup>38</sup> As previously noted, autonomy or self-determination, has been defined as 'the capacity to make and take actions that are keeping with one's values and belief.'<sup>39</sup> Respect for a person's right to autonomy and the ability to make choices and participate in the decision-making process. Perhaps, one of the most exclusive barriers to the full realisation of autonomous care is the question of capacity, actual or perceived. According to Dworkin,<sup>40</sup> autonomy is an essential and conceptually distinct subset of liberty. In essence, a person cannot separate their autonomy from their liberty.

#### *Why supporting autonomy is important*

Doyle and Gough<sup>41</sup> specify that people (including persons living with dementia) be given the material and emotional resources needed to enable them to be autonomous. Boyle<sup>42</sup> further elaborates by describing objective opportunities for exercising autonomy that allows for participation in socially meaningful activities and for making meaningful choices about one's life. In a practical sense, if we refer back to the garden, personal autonomy can be restored with the removal of hindering barriers, for example: allowing access to the garden without supervision or keypads on the door, as well as meaningful engagement, creating an environment where the person is allowed to express individualised choice and control, this could be as simple as choosing where to plant and what type of plants or flowers they would like to have in the garden

#### *Understanding key principles*

The Irish Health Information and Quality Authority (HIQA) acknowledges that promoting autonomy, and improving quality of life, may sometimes require a degree of risk. People who

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<sup>34</sup> Cahill pg 27

<sup>35</sup> Cantley & Bowes 2004

<sup>36</sup> Boyle 2008

<sup>37</sup> Nutffied Council in Bioethics 2009, Huges 2011)

<sup>38</sup> Edvardsson D, Winblad B, Sandman PO. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol.* 2008;**7**:362–7. doi: 10.1016/S1474-4422(08)70063-2.

<sup>39</sup> HSE National Consent Policy, 2014 in horseman)

<sup>40</sup> Dworkins (1988) p 20.

<sup>41</sup> Doyle & Gough (1991) in Boyle p 303

<sup>42</sup> Boyle (2008) p 303

use health and social care services are entitled to risk-taking's dignity and personal development. A positive approach to risk assessment acknowledges that risk-taking is part of a fulfilled life.<sup>43</sup>

Some of the fundamental principles of supporting autonomy include the following;<sup>44</sup>

1. Autonomy does not always involve total independence; it is essential to highlight that decisions may be supported as opposed to substituted
2. The UNCRPD endorses the promotion of personal autonomy through a rights-based approach to care.
3. Respect for autonomy means that every person (including those living with dementia) has a right to be involved in the decisions that affect their care.
4. The individual's will and preference replace the doctrine of 'best interests.'
5. Respect for autonomy means that every person has a right to consent to or refuse treatment—this includes residential aged care.

## Conclusion

This chapter has endeavoured to explore the interface between autonomy and residential aged care for persons living with dementia. In doing so, the paper's purpose was to identify how autonomous decision-making in residential aged care settings can best be supported and developed for persons living with dementia. This chapter focuses only briefly on each section but paints a picture of the general landscape of autonomy in care. The first section served as the contextual backdrop of the chapter by framing dementia through a disability, rights-based lens. The following section explored the concept of autonomy and practically highlighted how personal autonomy can be limited or restricted for several reasons. The final section had a shift in tone and focused on how autonomy can be developed and supported for persons living with dementia in residential aged care settings.

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<sup>43</sup> Morgan, S (2010) p 20-21

<sup>44</sup> HIQA, 2016 p 14

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## 4 Implicit Disability Bias in Reproductive Health Policy in Iceland: Is it enough to eliminate explicit discrimination?

**Megan Smith**, Centre for Disability Studies, University of Iceland

### Introduction

Over the last decade, Iceland has cultivated a national identity and tourist marketing strategy centered around elements of Nordic exceptionalism, notably feminism, LGBTQ friendliness, and social equality (Einarsdottir, 2020). Countering current global trends rolling back abortion rights, Iceland has also recently reformed outdated reproductive health legislation and policies, emphasizing wider and less restrictive access to abortion and increased support for women's reproductive autonomy. Further, in the aim to provide better prenatal care for pregnant people, Iceland is currently fielding different options for prenatal testing, specifically focused on non-invasive prenatal testing (NIPT), which envisions offering women increased and safer prenatal testing. While both the reform of abortion legislation, with the 2019 Pregnancy Interruption Law, and the proposals for introducing NIPT are widely seen as positive, there is a growing frustration amongst the disability rights movement regarding what is seen as implicit disability-related discrimination that underpins both these reformations. Reflected in the public statements from Althingi (Parliament of Iceland) and public dialogue preceding the 2019 Pregnancy Interruption Bill, disability rights were used as a motivating factor to reform the 1975 legislation on abortion and sterilization (Stjornarradid Islands, 2018, 2019). Yet, through the two years of dialogue, not only were disability rights perspectives from the disability movement sidelined but disability rights were appropriated by the reproductive rights movement as a reason to reform the old legislation, while simultaneously being used by the more conservative movement to put further constraints on new abortion legislation. As a result, the disability rights movement generally has viewed the reformation of the abortion legislation as going from being explicitly discriminatory to being implicitly discriminatory. Differentiating between explicit and implicit bias towards disability is particularly relevant when applied to public discourses such as with the 2019 Pregnancy Interruption Bill, as it highlights the increased difficulty for the disability rights community to address discrimination when current trends show explicit bias is declining, yet implicit, or unconscious, bias remains steadfast and can influence public debate and policy (Harder, Keller & Chopik, 2019).

The study of a societal level, long-term changes in explicit and implicit attitudes/biases towards social groups such as disability, has gained traction and importance in how we understand the future inclusion and equity of certain groups of people (Charlesworth & Banaji, 2019). This chapter aims to draw upon current research on long-term changes in explicit and implicit attitudes/biases towards disability, to explore how implicit bias often perpetuates disability-related discrimination and has the potential to impact future debates around reproductive health policy in Iceland.

To do so, this chapter will initially explore current research based on large-scale data sets from Harvard University's Project Implicit, regarding how explicit and implicit bias affects different social groups and how it can change over time. A focus will be on recent research that has compared how disability-related explicit and implicit bias compares to other social groups. In addition, concepts such as the 'expressivist critique' will be introduced to explore how Disability Studies have approached the experience and impact of implicit bias within the

disability community, particularly within the area of reproductive health. Finally, the chapter will trace how disability rights and disability-related bias influenced the drafting of the 2019 Pregnancy Interruption Bill. This will be explored through a preliminary review of government statements, civil society comments on the draft bills, reports, and news articles covering the debate from three of Iceland's largest media outlets from 2017-2020, including RUV (15 articles), Frettbladid (16 articles) and Morgunbladid (25 articles). What is presented here is a part of my on-going doctoral research on reproductive choices, prenatal screening and fetal impairment, examining policy and practice in Iceland and Ireland.

### **Evaluating long-term changes in explicit and implicit bias**

In pioneering research being conducted at Harvard University on long-term changes in explicit and implicit bias, a recent analysis by researchers Tessa Charlesworth and Mahzarin Banaji (2019) has reflected that implicit bias against disability, more so than most social groups, is a particularly difficult and persistent problem. Charlesworth, Navon, Rabinovich et al (2022) reflect that through a data set spanning 14 years, they have seen that implicit bias towards different social groups can change, but they have not seen any change regarding disability. She states,

[Implicit bias] changed for sexuality and race bias pretty dramatically. Sexuality biases dropped 64 percent over 14 years, but it hasn't changed at all for disability, age, or body weight bias. Disability bias over 14 years has only shifted by 3 percent. The disparity between the change in sexuality bias and the stability in disability bias is massive. (Rojas, 2022, p.B2)

A treasure trove of research has come from a large-scale, long-term study called Project Implicit, and particularly the Implicit Association Test (IAT) which for over two decades continuously solicited volunteers to take an online test evaluating explicit and implicit bias towards multiple social groups including race, sexual orientation, age, skin color, body weight, height, disability, political affiliation and nationality (Banaji & Greenwald, 2013). First debuted online in 1998, the Implicit Association Test (IAT) was developed to discover potential prejudices that reside beneath people's awareness, which were previously not able to be found through self-reporting methods (Sleek, 2018) The Implicit Association Test (IAT) in essence measures the strength of associations between concepts (i.e., black people, disabled people, gay people) and evaluations (e.g., good words, bad words) or stereotypes (e.g., athletic, clumsy, unintelligent) (Sleek, 2018).

Researchers have since used the IAT and data subsets from the millions of tests from Project Implicit to analyze facets of societal explicit and implicit bias. Some of the most significant recent studies have come from Charlesworth and Banaji (2019, 2021) who analyzed 4.4 million online tests collected over the last decade to investigate how implicit and explicit attitudes within six social groups have changed including sexuality, race, skin color, age, disability, and body size. Charlesworth and Banaji's (2019, 2021) recent analysis reflected that over the 14 years explicit bias towards all the social groups had moved towards neutrality, meaning non-bias. However, implicit bias towards age and disability did not change, and with body size attitudes even moved away from neutrality, meaning there has been an increase in bias regarding body size. This is in juxtaposition to the groups of sexuality, skin tone, and race, which revealed a dramatic reduction of bias even within the last decade. In a subsequent analysis, Charlesworth and Banaji (2021) estimate how long it would take for different social

groups to attain attitude/bias neutrality, given the current data. Regarding disability, they estimate it will take over 200 years for disability to reach a space of neutrality (Rojas, 2022). Similarly, a study conducted by Harder, Keller, and Chopik (2019) used data from Project Implicit to explore long-term trends in ableism and found that within their subset of 300,000 tests, inclusive of disabled and non-disabled respondents, implicit prejudice slightly increased over time (2004–2017), yet explicit bias showed a decline over the same period. Harder, Keller, and Chopik (2019) found that the biggest contributing factors towards changes in disability-related implicit and explicit prejudice were related to gender and contact with persons with disabilities, with women and increased contact with persons with disabilities indicating less explicit and implicit prejudice.

This recent trend in research exploring the different trajectories of societal level implicit and explicit attitudes/bias towards disability reflects the difficulty of discussing ableism and implicit discrimination towards disability in communities and spaces where explicit bias has noticeably reduced. As reflected in the research noted previously, studies have found a consistent reduction of explicit bias for disability, yet implicit bias remains steadfast and in some studies like those done by Harder, Keller, and Chopik (2019), has increased. It is a welcome and positive new trajectory of having less explicit bias towards disability, however, it leaves the issue of identifying and addressing the persistent implicit bias towards disability, which by its very definition are feelings individuals have toward groups that they do not endorse or even realize that they possess (Lai & Banaji, 2019; Nosek, Hawkins, & Frazier, 2011, 2012).

Disability Studies has also pioneered concepts around pervasive attitudes towards disability, notably through Adrienne Asch and Erik Parens' (2000) introduction of the 'expressivist critique', borne from early discussions around how explicit and implicit bias influence decisions and approaches to prenatal testing and disability-related selective abortion. It was argued that to selectively terminate a pregnancy based on an identifiable impairment or genetic trait is to *express* not only a negative view of that trait but also a negative valuation of the lives of people living with that trait (Asch & Parens, 2000; Boardman 2020). Navigating the persistent minefield around upholding both disability rights and reproductive rights, Adrienne Asch (1999, 2005) argued that the problem with prenatal testing and prenatal genetic testing was not that it often could lead to abortion, but rather it was ethically problematic because it expresses a negative value upon those living with those conditions, and therefore cyclically influence potential choices for testing such conditions. Like Asch, other influential Disability Studies researchers such as Shakespeare (1998), Wasserman (2006), and Garland-Thomson (2017) have used expanded expressivist critiques to argue that prenatal screening has signaled 'eugenic elimination' to certain people with disabilities and their families. Bryant and Shakespeare (2022) recently noted that with the rapid advancement of prenatal testing, notably noninvasive prenatal testing (NIPT) and fetal whole genome sequencing, the process is no longer obviously coercive but rather "eugenics through the back door" (p.46). In essence, the rapid advancement and expansion of prenatal testing technology have evolved from screening practices that were seen as explicitly discriminatory, to recent practices and policies that are implicitly discriminatory. The expressivist critique however is not without critics. Researchers like Eva Feder Kittay (2005) and Jamie Nelson (2000), argue that the act of choosing to test and selectively abort does not necessarily correlate with bias against people with disabilities, and could be influenced by factors independent of disability. Others such as Jonathan Glover

(2006) and Stephen Wilkinson (2010) take issue with the expressivist critique as they do not believe that commonly held disability bias, which Glover (2006, p.35) labels as “ugly attitudes,” influences people's reproductive decision making. Glover (2006) relays that the expressivist objection to prenatal testing and selective abortion can be dispelled by reassuring people with disabilities that reproductive decisions are not motivated by bias but can be resolved by taking actions to create better social and structural supports for children with disabilities and their families. Despite some validity of such critiques, the expressivist view of prenatal testing and selective abortion recognizes the impact of deeply rooted disability bias, particularly implicit bias, on our reproductive decision-making, which will not be resolved by environmental or structural changes alone. As Chris Kaposy (2022) states, “it is highly likely that our reproductive decisions are influenced by unacknowledged or disavowed cultural prejudices about disabilities and people with disabilities.” (p.22) While imperfect, the expressivist critique does provide a theoretical framework to understand the impact that implicit disability bias can have on reproductive health practices and the difficulty of discussing such issues when it comes to policymaking. Coupling the recent research on long-term trends around implicit and explicit disability bias, with concepts such as the ‘expressivist critique’, provides a unique lens for examining the discussions and evolution of the 2019 Pregnancy Interruption Law in Iceland.

### **Reforming Abortion Legislation in Iceland**

By the fall of 2019, there was palpable exhaustion that permeated the disability rights community in Iceland. After two years of intense public debate around reforming the 1975 Act on Counselling and Education regarding Sex and Childbirth and on Abortion and Sterilisation Procedures, the new Pregnancy Interruption Bill was finally adopted by Althingi (Parliament of Iceland) earlier in 2019. Disability rights community leaders and activists felt burnt out and resigned to a law that was widely celebrated as one of the most progressive pieces of abortion legislation in Europe, yet for many, was laced with disability-related discrimination. The main point of contention for the disability community and their allies was the intention they perceived behind putting the term limit for unrestricted abortion at 22 weeks, extending beyond the common 20-week prenatal screening for chromosomal anomalies and other impairments. By tracing the development of the Pregnancy Interruption Bill through reviewing governmental statements, media coverage, and civil society statements during the drafting and consultation process, it highlights how disability rights objectives were appropriated by both sides of the abortion debate, how voices and opinions from the disability community were sidelined, and how narratives around disability shifted from being explicitly discriminatory to a more implicit form.

For over a decade Iceland’s feminist movement had been advocating to reform the Icelandic Act No. 25/1975 which legislated abortion in Iceland. Despite progressive practices, Iceland had retained the 1975 legislation which by 2018, was one of the Nordic countries most restrictive abortion laws on paper. According to the Act, women could get an abortion up to 16 weeks of pregnancy with the condition that she was evaluated and approved by two medical professionals. The reason for the abortion was also required to be justified under the limited conditions of either medical or social reasons. The act further stipulated that a woman could obtain an abortion after 16 weeks only “should there be a great likelihood of malformation, genetic fault or fetal damage” (Lög um ráðgjöf og fræðslu varðandi kynlíf og barneignir, p. 3). In addition, the Act outlined that after an abortion women must be instructed and counseled on the use of contraception. Although these policies were often treated as a check box activity,

practitioners and care providers still had the authority to deny a pregnant person an abortion based on the parameters set out in the 1975 law and to create unnecessary barriers for many women looking for an abortion. As such, there was a strong feminist push to align the legislation with the practice of accessing abortion in Iceland, providing women and pregnant people full autonomy over their bodies and reproductive choices.

In September of 2018, the Minister of Health, Svandís Svavarsdóttir, submitted the first draft bill to Althingi for further consideration on term limits and to gather public comment through the government consultation portal. In the official announcement published in October 2018 on Stjornarradid Islands, the statement emphasizes that in the drafting of the bill high priority was placed on ensuring that the new legislation would be fully aligned with the UN Convention on the Rights of Persons with Disabilities (Stjornarradid Islands, 2018). It further elaborates that a reason for reforming the past legislation was due in part to it being explicitly discriminatory against persons with disabilities with Article 11 of the 1975 Act stating, "if there is a high probability of malformation, genetic defects or damage to the fetus" (Lög um ráðgjöf og fræðslu varðandi kynlíf og barneignir, p. 3). Citing Article 8 of the UNCRPD on awareness raising which requests States to work against stereotypes and bias relating to people with disabilities, the statement stresses that this new draft bill on abortion will not only uphold women's reproductive autonomy but eliminate the current explicit disability-related discrimination in the text, which counters Iceland's commitment to the UNCRPD (Stjornarradid Islands, 2018). Official statements from the Ministry of the Prime Minister (Stjornarradid Island, 2018) and the Ministry of Health (September 2018) also included that the main motivation behind reforming the existing legislation was to eliminate explicit discrimination against persons with disabilities and to ensure the new abortion legislation would be aligned with the UNCRPD.

Starting in 2016, the Minister of Health initiated an expert working group to provide recommendations and contribute to the first draft of the bill.<sup>45</sup> The expert group which consisted of professionals from medical and related fields, including a midwife and sexual education educator, a specialist in obstetrics and gynecology, and a social worker, submitted their recommendations to the Ministry in November 2016. Notably, the working group recommended that the term limit be placed at 22 weeks (Heildarendurskoðun laga nr. 25/1975, p. 31). Within their extensive report, the expert group lays out arguments for two different term limits for the new legislation, one being at 16 weeks and the other at 22 weeks. Ultimately recommending the latter, the expert committee interestingly cites that there would be increased opportunity for disability discrimination at 16 weeks, as there would need to be an explicit provision regarding the circumstances for aborting the fetus after 16 weeks. The report states,

Authorizations for termination of pregnancy after the 16th week may, however, be of such a nature that they promote discrimination against persons with disabilities. Exemptions for abortions after 16 weeks of pregnancy according to Article 10, paragraphs 2, and 3 of the current law have so far been granted if abnormalities have been revealed during the

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<sup>45</sup> Heildarendurskoðun laga nr. 25/1975, um ráðgjöf og fræðslu varðandi kynlíf og barneignir og um fóstureyðingar og ófrjósemisaðgerðir

examination of the fetus that indicates that a person will be born with varying degrees of mental or physical disability. It can be difficult to present a provision that provides authorizations like this without addressing specific groups of individuals, such as disabled individuals. (Heildarendurskoðun laga nr. 25/1975, p. 32)

In their reasoning behind extending the term limit to 22 weeks, the expert group notes that this time frame will uphold to the highest degree a woman's right to self-determination and bodily autonomy and that at 22 weeks the fetus is considered viable outside the womb. They further elaborate that this would eliminate any possible discrimination against people with disabilities as unlike the current law, there need not be an explicit clause in the case of fetal impairment. Noting here that women would have access to abortion as approved by a medical professional after 22 weeks should the mother or fetus's health be endangered.

During the expert groups deliberation process they received 27 submissions from stakeholders including from the most prominent disability rights organizations, like the Downs syndrome association and the National Association for Intellectual Disability. Many of the submissions from the disability community expressed that while removing the explicit clause relating to fetal impairment was welcome. However, by putting the term limit at 22 weeks the legislation and the government signaled to the Icelandic public that it was critical to place the term limit after the 20-week 'abnormality' scan so that potential parents could indeed abort (Heildarendurskoðun laga nr. 25/1975, p. 54).

When the draft bill was submitted to Althingi for public input, the Minister of Health changed the term limit for unrestricted abortion to 18 weeks, countering the recommendations in the expert report (Lög um þungunarrof, n. 2018). Media outlets reported early in September 2018, welcoming the reformed legislation for up to 18 weeks (Ragnarsdóttir, Sept.28, 2018; Eidsson, October 5, 2018; Pálmadóttir, Oct 3, 2018). However, after a month of submissions and inputs from the medical community, the bill was quickly amended to extend the term limit up to 22 weeks (Lög um þungunarrof, n. 2018). In addition to the seemingly abrupt manner that the term limit was amended, high-profile medical professionals were explicitly citing the 20-week scan as a reason for the expanded term limit.

Hulda Hjartardóttir, chief physician of Obstetrics at Landspítali, commented early on that,

This is the time we have planned and planned our follow-up during pregnancy, for example regarding ultrasounds, we have done this routine ultrasound at 20 weeks and can then respond if something comes up that requires further research that we try to work very quickly so that we have been able to identify the nature of the problem before 22 weeks" (Erlendsdóttir, Oct 25, 2018)

There was strong opposition from the disability rights community and different allies for what was seen as trading one explicit discriminatory clause for a more underhanded form of discrimination spurred, as many activists felt, by deeply held disability bias in Icelandic society. The University of Iceland's Institute for Ethics, which the government solicited inputs from on multiple occasions, took a measured approach and was one of the few submissions outside of the disability community to note that while not explicit, the 22-week benchmark still expresses, and therefore perpetuates, discriminatory attitudes towards people with disabilities. In their closing remarks the University of Iceland Institute of Ethics states,

The Institute of Ethics concludes that it is important not to rush the processing of this bill too much [...] careful consideration must be given to the tension between this bill and the United Nations Convention on the Rights of Persons with Disabilities. At stake here are fundamental questions and issues about the moral status of the fetus, the rights of disabled people, and women's right to self-determination, which need a deep and informed discussion in society. (University of Iceland Institute of Ethics, 2018 p 5)

Unlike the Institute of Ethics which wanted to ensure the utmost bodily autonomy and rights for women as well as prevent the perpetuation of disability-related discrimination, a record number of submissions made by anti-abortion religious groups invoked the UNCRPD and protect the life of a disabled fetus to promote their opinion to further restrict abortion access (Hjaltadóttir, May 3, 2018; Pálsson, May 2, 2019; Johansson, May 5, 2019). In addition to religious organizations being seen to appropriate disability rights language and ideas, conservative members of parliament, notably the Peoples Party, also publicly cited discrimination against disabled fetuses as a reason to limit abortion access (Pálsson, May 2, 2019; Johansson, May 8, 2019). Many activists within this debate from the disability rights movement, were overwhelmingly pro-choice and wanted the most unrestricted access to reproductive health services and abortion. However, the virulent appropriation of disability rights by the conservative movement not only seeded wariness between the feminist and disability rights community but largely overshadowed the true concern about how to avoid disability-based discrimination, explicit or implicit, while maintaining the most expansive and unrestricted reproductive rights. In parallel, there was little recognition from the mainstream feminist movement or progressive members of parliament, that just because explicit discriminatory clauses have been removed to align with the UNCRPD, it does not mean that disability-based discrimination within the new legislation was eliminated.

While this piece of legislation has passed without the disability community feeling fully heard or understood, other reproductive health policies, such as non-invasive prenatal testing (NIPT) are imminently on the horizon and present the same quagmire of trying to combat practices and policies largely influenced by implicit bias.

## Conclusion

Explicit bias towards disability has slowly improved through decades of relentless activism, civil rights legislation, infiltration of the media, and increased visibility within everyday life. However, it is an implicit bias where we find quicksand. Reproductive health debates in Iceland reflect how widely celebrated progressive legislation can still perpetuate discrimination if left uninterrogated. While it is seductive to say that it will take further awareness-raising and changing mindsets, recent studies (Lindner, Nosek, & Graser, 2012) have ironically noted that changing mindsets can sometimes *increase* discrimination. Like, instructing people to assert that they are objective decision-makers before a hiring decision increases gender and age discrimination. Particularly relevant is Lai & Banaji (2019) finding that “[there is] a delicacy of inducing mindsets to alter behavior. Whereas the motivation to be non-prejudiced may lead to reduced prejudice, thinking of oneself as non-prejudiced may ironically increase discrimination” (p. 9). In the coming discussions and activism around different and new reproductive rights policies, this is where we can start, by recognizing that we may have prejudices and biases, but are motivated toward eliminating them.

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## 5 Discussing End of Life Care Options with People with Intellectual Disabilities via Zoom: Preliminary Observations from the Pilot and FGDs

**Marissa Diaz**

### **Abstract**

Research undertaken during the COVID-19 pandemic will be characterized by the ingenuity and persistence of researchers that were forced to shape their work around an uncertain and changing global emergency. Given these circumstances, this article describes the preliminary results of a research project that was conceived, developed, and ultimately deployed during the first two years of the pandemic. Focusing on people with intellectual disabilities and their views choosing where to spend end-of-life, online focus group discussions were held via Zoom. Observations include technical issues when using Zoom for research, illustrations facilitating discussion, and the focus of discussion going back to the deaths of participants' loved ones. This research project, although small in scope, is an example that inclusive research can be done safely and remotely. However, researchers must be aware of the myriad of complications and issues that arise when doing research of this nature online.

### **Introduction**

Trying out an unfamiliar methodology, either due to its novelty or the inexperience of the researcher, can prove to be a daunting task. In the case of this research project, both aspects came into play as I began to formulate my research plan when I started my PhD in late 2019. Like other academics worldwide, my research was molded around the COVID-19 pandemic and the limitations imposed by it. Early on, it became incredibly clear that conducting my data collection online would be best not only for my safety but also for the safety of my co-researchers and participants. Taking into consideration the practicalities of conducting research virtually (as detailed in my previous chapter), I knew that my co-researchers and myself would be facing many challenges as we continued with the project, especially considering the subject matter: end-of-life care. Despite complications arising with travel issues due to COVID-19, with the assistance of NUI Galway and the support of my co-researchers, I was able to coordinate two focus group discussions (FGDs) in March and April of 2022 following the initial pilot study conducted in September 2020. The purpose of this chapter is to describe observations made during the pilot and two FGDs with an aim to inform my future publications and PhD thesis overall.

My research focuses on end-of-life care for people with intellectual disabilities (PWID), specifically attempting to examine what this population thinks about accessing end-of-life care in the future in order to distinguish perceived facilitators and barriers. In an effort to make this research more inclusive of the views of PWID, I work with co-researchers with intellectual disabilities from the Inclusive Research Network (IRN) based in Ireland. In moderating FGDs centered on choosing to go to hospice or staying at home to receive end-of-life care, I aimed to explore the perspectives of this population on the motivations behind choosing between one location and another.

Data collection was carried out in Ireland, where PWID make up 1.4% of the population (Central Statistics Office, 2016) but die younger than the general population (Doyle, O'Sullivan,

Craig, & McConkey, 2021). Ireland's general population is rapidly aging, which will necessitate efficient and effective end-of-life care for people with a variety of needs in the future (Kane et al., 2015). To complicate matters for PWID, Ireland's aging and disability services are delivered separately (Leahy, 2018), which has larger implications for the country's aging population with intellectual disabilities: they are often in intellectual disability services for their entire lives and as they age they become more at risk of losing these services (Bigby, 1997). Clearly, quality and timely end-of-life care for this population relies on strong and cohesive links between intellectual disability services and palliative care services. However, a study conducted in Ireland revealed that staff from both services are not confident in their ability to deliver palliative care to this population, despite their willingness to do so (Ryan, Guerin, Dodd, & McEvoy, 2011). In summary, there is a need to connect palliative care and intellectual disability services with strong links and co-ordination in order to achieve good end-of-life care for this population.

While I have not commenced data analysis and therefore cannot draw any conclusions on the themes that arose from the discussions, these observations are interesting from a methodological standpoint, especially considering the population. Within academia, the views of PWID have been remained relatively unexplored until the middle of the last century (Walmsley & Johnson, 2003). The overwhelming majority of research participants in existing studies focusing on PWID's palliative care needs and access to these services are not members of this population (Adam, Sleeman, Brearley, Hunt, & Tuffrey-Wijne, 2020). Previous research suggests that PWID have an incomplete understanding of death in all its complexity (McEvoy, Treacy, & Quigley, 2017); and this is likely compounded by resistance by family and staff to bring up the subject with this population (Wiese, Stancliffe, Read, Jeltos, & Clayton, 2015) and their unfamiliarity with how to have these conversations with PWID (Kirkendall, Linton, & Farris, 2017). Although there are challenges to conducting research with this population (Sigstad, 2014), their lived experiences are not only beneficial to researchers but also encouraging for participants, reaffirming that their voices need to be heard. For instance, self-advocacy groups like the IRN focus on doing research with people with intellectual disabilities on topics that affect their lives, not only giving them voice but giving them the skills needed to enact change through research (García Iriarte et al., 2021). When building end-of-life resources for the future, the views of PWID must be investigated in order to meet their needs and learn from their lived experiences.

### Three Observations from the Pilot and FGDs

I have arranged my anecdotal notes under three broad themes: **Using Zoom**, **Illustrations**, and **Reference to Past Deaths**. Within each section, I cover what we knew from the literature and the focus group and pilots. Each section ends with a summarizing sentence.

#### *Using Zoom*

Considering the near worldwide shift to social interactions being conducted by electronic media due to COVID-19, we will undoubtedly see an increase in research conducted by Zoom and publications outlining the methodologies guiding this research. While qualitative research conducted via the internet is nothing new, it is important that researchers consider its limitations. For example, use of internet technologies inherently limits the participants to those who have a device and internet connection and have a degree of literacy in operating a computer (Kroll, Barbour, & Harris, 2007). Concerning PWID and their access to the internet, there are numerous inequalities and impairments with communication, typing, sequential reasoning, etc.

(Chadwick, Wesson, & Fullwood, 2013). However, this population may have more access to the internet as computer prices continue to decline and the reach of broadband and WiFi expands (Boxall & Ralph, 2009). Due to the practicalities of continuing to live and work during a pandemic, many organizations moved online, including the IRN and other inclusive research realms (Hwang et al., 2022). Zoom has also been used in fields outside of research, such as art therapy for PWID (Power, Dolby, & Thorne, 2021).

Reflecting back on previous literature, I took notes of previous experiences and built my Zoom calls around them in anticipation of similar challenges described in the text. The pilot reinforced the points listed below, but I had to keep the audience in mind. My co-researchers who tested the pilot are from the IRN, so they likely had more experience with research than other PWIDs. Holding a practice session to work on technical issues (Archibald, Ambagtsheer, Casey, & Lawless, 2019), suggesting that participants call in from a private area when possible (Reñosa et al., 2021), and reiterating the need for maintaining the confidentiality of the FGDs (Archibald et al., 2019) were employed for this research project in order to avoid technical and ethical issues.

While the preparations I made contributed to a relatively smooth experience and I had practice session before the first focus group session in March, there were multiple technical issues when the actual FGDs were held. Absenteeism was an issue for both sessions. About half of the participants anticipated did not attend. This issue has been identified in previous research conducted online (Deakin & Wakefield, 2014). In both sessions, we had to wait for participants to connect (ultimately some of them never joined) and sometimes it was challenging to determine whether someone was having issues with their connection or was no longer interested in participating. Connectivity issues did not stop once the session had begun. During one session, one person dropped out multiple times. As described in the literature (Sipes, Roberts, & Mullan, 2022), it was not always clear whether someone dropped due to emotional distress or their connection was bad. Luckily, participants always made it clear that their connection had dropped once they joined back in. Beyond dropping out completely we had to contend to time lags, both with the audio and video components. Despite the technical issues, my co-researchers, their supporters, and participants indicated that their experience was positive. Emails sent by participants after the fact indicated that they appreciated the experience and opportunity to talk.

In this small, remote (Zoom) setting, this population appeared comfortable with the topic, but technical issues (connectivity, sound, etc.) prove to be a barrier that requires thorough planning to overcome.

### **Illustrations**

Illustrations are a common methodological tool utilized by researchers when conducting qualitative research with PWID. Like other research methods that invite the participants to use photography to investigate opinions or phenomena (Aldridge, 2007; Povee, Bishop, & Roberts, 2014), illustrations can help facilitate a dialogue with participants who may have communication issues. Previous qualitative research with this population has often accompanied a story or vignette. The use of illustrations alongside a story is commonly used for research on end of life issues. Death is an abstract concept, and illustrations help those with cognitive difficulties contextualize the concept. Supplementing my Zoom focus group was a PowerPoint presentation, which both guided the questions asked and the organization of the

call itself. The format was based on EasyRead guides. Feedback was received from my co-researchers from the pilot and researchers with previous experience researching the views of PWID. Illustrations were commissioned from an artist who had previously worked with another researcher from DARE. I sent the artist complete details on how many illustrations I wanted and what they should look like.

I found the images to be conducive for inviting insights and comments on the lives of the people depicted and the choices they had to make. Taking a cue from previous research (Hollomotz, 2018), I made sure that the buildings and interiors looked unmistakably Irish so that my participants would recognize what I was trying to convey. However, participants zeroed in on aspects that I did not consider important. For example, one of the people described in the presentation had a slight frown while in his hospice bed, which the participants picked up on. This is a significant feature of this research, since the illustrations may influence answers. However, the reaction to the images was positive, both from the co-researchers and the participants. These observations reinforced what previous research told me: PWID are not a homogenous group and it can be difficult to develop illustrations and other tools that are "one size fits all".

A methodology that includes illustrations that supplement a story can be engaging for a focus group with this population, but said illustrations must be carefully planned and drawn so as to not confuse participants or introduce bias.

### Reference to Past Deaths

When asked about their own wishes concerning death and dying, this population has demonstrated repeatedly that they have the same opinions, fears, and wishes as the general population. In previous research, PWID have said it is important to be there for the dying person while at the same time respecting their last wishes (Bekkema, de Veer, Hertogh, & Francke, 2016). Other research from the Irish context indicates that there is a desire from PWID and their families to create a plan that ensures that their wishes will be respected at end of life (Cithambaram, Duffy, & Courtney, 2020). In summary, while there is a relatively small amount of research on the views of PWID, this research shows that PWID are not only able to talk about this sensitive issue but have many opinions about it.

As I constructed the research question, I was unsure how comfortable the participants would feel sharing their experiences about death, especially with someone who is both a stranger and a foreigner. We talked about the death of partners, siblings, and parents. Co-researchers also chimed in with their own personal experiences with death. A careful balance had to be maintained. While the goal of this research was to investigate the views of this population, I was wary of upsetting them. However, upon reflecting on my own experiences and opinions about end of life care, I realized that the former absolutely informed the latter. After the focus groups were over, the personal experiences of the participants rang in my head, experiences I had not heard before from this population. Since this population has historically not lived to old age until relatively recently, discussions about the deaths of their partners and parents became even more striking.

Opinions appeared to be largely formed by prior experience, specifically the deaths of their parents, relatives, or friends.

## Conclusion

The observations in this article cannot be divorced from the context in which the pilot and focus groups were conducted – during a global pandemic. COVID-19 has killed millions of people, given long-lasting illness and disability to a yet unknown number of people, and has severely limited national and international travel until very recently. Any attempt to understand this research and its results must be done recalling that COVID-19 affected nearly every aspect of our lives, including PWID. Research shows that the pandemic had a significant effect on the lives of PWID, including on their relationships and jobs that affected their daily routines (Embregts et al., 2022). This is significant because their social circles tend to be smaller than those of the general population (Kamstra, van der Putten, & Vlaskamp, 2015; Merrells, Buchanan, & Waters, 2019). When looking at both the methodology and findings from this project, it is important to remember it was during unprecedented times and affected the participants, co-researcher, and myself in a myriad of ways.

If we have taken away any lessons during COVID-19, it is my sincere hope that academics commit to accessibility, particularly within online spaces. This is far from an easy task. If accessibility online was not an issue then it would not still be an important topic today. For PWID, accessible spaces online are also a challenge since PWID are far from a homogenous group, and delivering quality and understandable information to a group with diverse needs requires multidisciplinary prowess and resources (Terras, Jarrett, & McGregor, 2021). However, change has to start from somewhere, and hopefully recent developments within the online sphere will include people with different disabilities to actively participate in online life.

While the experience described was not without bumps in the road, my PhD project shows that using Zoom and illustrations can facilitate discussions with PWID focusing on emotional topics, such as the deaths of loved ones. If the use of online technologies like Zoom and facilitators such as illustrations can further include PWID in academic research (even during global pandemics), then it would foster further collaboration in other fields as well. Perhaps this collaboration is no more important than when discussing end of life. After all, dying is a collaborative effort; beyond the individual, there are families, healthcare services, social services, and spiritual services involved. It only makes sense that research concerning end of life is all-encompassing and facilitates multidisciplinary co-operation, most importantly with PWID who deserve a good death as well as a good life.

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## 6 Emerging findings: Analysis and dissemination in participatory research

**María Gómez-Carrillo de Castro**

### Summary

This chapter explores the challenges encountered during my co-researched project in the phase of analysis and dissemination. Participation was more challenging during this phase, due to the subsiding excitement of the project and the complexity of the task. Further, the online format adopted due to personal preferences and the pandemic became an obstacle to introduce other working dynamics. Secondly, the analysis can have an emotional toll on persons with disabilities due to their own personal experience, which needs to be considered when planning the analysis. Lastly, the chapter includes some experiences during the dissemination efforts, which reflect on how participatory research evidence is received by the broader academic field.

Keywords: analysis, dissemination, participatory research, human rights,

### Introduction

This project explored the use of human rights based participatory research methodologies with persons with disabilities in social policy in the Spanish context.

During the period from January 2021 to September 2022, I worked with two groups of co-researchers with disabilities. One group was part of the Disabled Person's Organisation CEPAMA, an organisation of autistic women in Spain, and a second group were people with learning disabilities who are linked to some type of services which are part of Plena Inclusión Madrid.

Each group conducted a research project, including the phase of analysis and dissemination. Involving people with disabilities during the phase of analysis and dissemination is rare (Rix et al, 2021), as is involvement in general (Jurkowski, 2008).

Nind found that involvement of people with learning disabilities in the analysis is also scarce (Nind, 2008). In this paper, I present how we conducted the analysis and what difficulties we encountered.

### Methodology

In this project, I followed the human rights based participatory research methodology presented by Arstein-Kerslake et al. (2020), which proposes the Convention on the Rights of Persons with Disabilities (CRPD) as framework to guide the research. One of the main principles is that people with disabilities must always hold control over the research. In this project, my co-researchers were engaged at all stages equally. This is in line with Walmsley & Johnson's proposal (2003) of inclusive research, who underline that inclusive research is collaborative and must involve people with learning disabilities in the process of doing the research, accessing, and representing their views and experiences and that people with learning disabilities must exert some control over process and outcomes (Walmsley and Johnson, 2003 cited in Nind, 2017).

I used autoethnography and reflexivity tools to observe how we worked together, through video recordings, note taking and diary keeping. Qualitative research has been said to be about

“implementing the goals of social justice and radical, progressive democracy”, and “expose and critique the forms of inequality and discrimination that operate in daily life” (Garoian & Gaudelius, 2008 in Giardina & Denzin, 2010, pp.15-16). Participatory research and autoethnography as methods acknowledge the crisis of representation in social sciences (Prasad & Prasad, 2019). Autoethnography offers unique possibilities to gain an in-depth understanding of social and cultural contexts as well as research topics through description and reflective analysis of personal, lived experiences (Syrjälä & Norrgrann, 2018). Ellis et al. (2011) define it as a qualitative methodology in which research and writing seek to describe and systematically analyse personal experience in order to understand a cultural experience.

Autoethnographic projects should focus on the following core ideals:

- *“Recognizing the limits of scientific knowledge (what can be known or explained), particularly regarding identities, lives, and relationships, and creating nuanced, complex, and specific accounts of personal/cultural experience*
- *Connecting personal (insider) experience, insights, and knowledge to larger (relational, cultural, political) conversations, contexts, and conventions*
- *Answering the call to narrative and storytelling and placing equal importance on intellect/knowledge and aesthetics/artistic craft*
- *Attending to the ethical implications of their work for themselves, their participants, and their readers/audiences“*

(Adams, Holman Jones & Ellis, 2015, p.27)

In this paper, I focus on the experience of doing analysis and dissemination together as part of the wider process of research.

### The projects

During the past two years, I was part of two co-researched projects: one led by persons with learning disabilities from Madrid, Spain, and one led by a group of autistic women who are part of a Disabled People Organisation (DPO) called CEPAMA, which works countrywide.

#### *Co-researcher group with learning disabilities*

The first group chose to research the impact of Covid-19 on the lives of persons with learning disabilities in Madrid, Spain. The group conducted a survey with 118 respondents and subsequently 7 focus group discussions, with a focus on the differences according to the participant’s living arrangement (home with family, group home or residential care). The research tools were tested with volunteers from Galicia, Spain. The analysis of the survey was done with excel and visualisation tools. All surveys were conducted orally by the co-researchers in pairs or with me as notetaker. Another co-researcher transferred all the survey results onto an excel sheet which we designed together.

The focus group results were analysed in different ways. First, we rewatched the recordings and stopped them after a couple of minutes to discuss the participants’ responses. This method was a bit tiresome and difficult to follow. Eventually, after having watched the recordings, I selected parts of the transcripts which I thought we had missed during our listening sessions or which I found interesting to discuss. I took notes of our observations and analysis in a power point presentation in screensharing mode. These slides were the basis of the report, which I put together. The analysis continued during the reading and editing of the report, which we re-read

several times. Additionally, we prepared a summary and a presentation for the European Sociology Association Conference 2021 and to launch the report. The preparation of these two presentations and summaries were also excellent opportunities to pick up our debates around the findings, what implications they had and what they meant for us, for people with learning disabilities and for social policy. I selected some citations to illustrate our findings, which my co-researchers verified. It was an iterative process, that was difficult to end, as new reflections and personal experiences came to surface. However, my co-researchers wanted to finish the report and the project, which had been nine months longer than initially planned.

The feedback I received with regards to this phase was that it was less interesting than the previous one (fieldwork), and that it was tiresome and slow. The group agreed that it was a difficult phase. All of them had preferred conducting the focus group and talking to their peers about their experience of the pandemic and lockdown and exploring other realities immediately, rather than retrospectively over recordings and text.

The analysis phase was hard and some of the co-researchers with learning disabilities described some working sessions as ‘boring’. To make the process more tolerable and appealing, we shortened the working sessions and included an additional break to make it easier to rewatch. Despite the hard work, no team member wanted to skip a working session. At times, we asked ourselves whether the experiences were good or bad, what barriers and how things could have been different. This led to breakthroughs which sparked the interest in the conversation, including contrasts with the co-researchers’ own life experience. The research process produced opportunities to reflect on life experiences and the different situations people with learning disabilities live daily.

The dissemination efforts took place at different moments throughout the project. Firstly, my co-researchers presented their research project informally to the inclusive research group from the University of Girona. This group invited us to publish our working methodology in an online publication to celebrate their 10<sup>th</sup> anniversary.<sup>1</sup>

Secondly, the group presented our initial findings at the ESA Conference 2021 in August, during which we shared our panel with two other speakers. One of the speakers followed our presentation with interest and adapted his language to link his findings to our study, and challenge some of our conclusions. However, the second speaker made an inaccessible presentation including grand theories, and many authors. I tried to explain what he was saying to my co-researchers with little success, as much of what he said was difficult to understand for me as well.

Lastly, we launched our report at the end of March 2022. The session was recorded and will be posted on the umbrella organisation’s website together with our report. The presentation was online and most of the attendees were people with learning disabilities, a couple of scholars

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<sup>1</sup> This publication is available here: <https://dugi-doc.udg.edu/bitstream/handle/10256/21054/InvestigacionInclusiva.pdf?sequence=4&isAllowed=y> (pp. 67-78)

and support staff. The presentation was thirty minutes long, followed by a conversation with the audience.

The dissemination activities were a highlight for the co-researchers with learning disabilities, and, whenever possible, we all participated in presenting our research project and findings, e.g., at the ESA 2021 conference. In general, the group enjoyed engaging with participants, other researchers, and the public, to exchange ideas or to present their work.

### **CEPAMA**

The second group, part of the DPO, CEPAMA, was interested in looking at different aspects affecting the lives of autistic women: the access to a diagnosis and a disability certificate and how this played out in higher education, employment, and access to health. We co-designed an exploratory study and developed interview guidelines. These were tested with autistic women from Latin-America that follow CEPAMA's work. Secondly, we prepared a PowerPoint presentation to support the interviewees and a written format for those participants who preferred being interviewed via email in written form. In total, we conducted 29 interviews. Four co-researchers conducted the interviews pairing up with me or with each other. All interviews were transcribed and anonymised.

The analysis was done in different ways. Firstly, we used an exercise to tap into collective knowledge called the Root-Cause-Tree-Tool.<sup>2</sup> This helped us develop some initial codes and made us aware of some limitations of our sampling or the need for further research in specific areas. It helped my co-researchers to think about different levels of analysis (descriptive and interpretative). During the actual analysis of the transcriptions, they became aware of gaps in the tree we had created and the tension between expecting a specific finding and different results. It was a useful tool to allow for all co-researchers to contribute (either orally or in written form), and to spark further debates.

Based on this exercise, we developed a first set of codes, which was expanded after the first rounds of analysis. We met after two rounds of analysis to discuss additional codes, clarify concepts, and share our experiences, concerns, and the limitations we identified.

Secondly, we split up the co-researchers interested in engaging in coding and analysis in pairs or in groups of three. Several interviews were assigned to each pair. Each co-researcher coded the interviews in their preferred way (words, number, colours agreed upon collectively) and then shared it with their pair. The same interviews were usually assigned to two different pairs, who could contrast their analysis among pairs in a second step, to ensure consistency in the use of codes and to identify potential differences in interpretation. In the second half of the analysis, this was reduced to two or three co-researchers coding the same interviews to reduce the workload.

Lastly, I put together all the coded interviews on a software analysis programme (ATLAS TI) and drafted the report with the summaries and comments sent by my co-researchers. This report

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<sup>2</sup> See more here: <https://www.boingboing.org.uk/youth-activism-cornwall-co-research/>

will be reviewed by all co-researchers (not only those involved in the analysis) and edited to be published in Fall 2022.

As part of our dissemination, CEPAMA organised an event in May 2021 around the right to employment, during which we presented our research project. Secondly, we participated in a seminar organised by a German University and imparted a lecture twice in a human rights course organised by Instituto Derechos Humanos Gregorio Peces Barba (UC3M). In 2022, we presented our working methodology at the annual Conference organised by the Disability and Human Rights Observatory of the Instituto Superior de Ciências Sociais e Políticas on human rights-based participatory research methodology.

In a different line, we also met with the Spanish Royal Patronage for Disability and in a separate meeting, with the General Director for Disability Policy.

## Discussion

### *Make the implicit explicit*

One of the challenges of making a research process participatory and accessible lies in making the implicit explicit. In the same lines, other authors have expressed it as moving interpretation from an *implicit* process to an *explicit* process, making ‘conventions of interpretation clear’ (Brown et al., [1991](#), p. 42 in Byrne, 2009).

To me, this meant a process of retelling what we were understanding and what the implications of that understanding were. I became aware of the implications of the different subphases in analysis while facilitating it or doing it myself. Conducting analysis involves engaging with the data, contrasting it with the co-researchers’ own experience and with what the literature says, as well as with whatever had been discussed previously. Ideas form but might change as the analysis advances. Secondly, the conversations and the ideas will not come up in an orderly manner but must be examined and sorted within the whole research process. This iterative process can be difficult to make accessible and support without taking over control. It became clear to me that analysis is time consuming and happens throughout the day, not just when physically sat at a desk. Unfortunately, many people with disabilities may not have the time to keep revisiting the research project or it can result too demanding.

### *Weaving all information together*

The analysis phase entails bringing a lot of information to the conversation at the same time, which can be overwhelming. Moreover, the cost of engaging with the analysis can be high, as in the case of persons with lived experience, it can lead to reflections on their own experience and identity. My co-researchers told me how it affected them when it resonated with them and became, at times, too intense. We had various conversations (virtual and written) about how to deal with the work and the need to step back at times. During our group discussions, my co-researchers were concerned with how the research would represent or *misrepresent* the situation of autistic women. We reflected together on the limits of the research, what we could explain and what would be overly simplistic or overlooking other factors. We discussed the ownership of narrative and the limits of interpretation. One of the issues I felt compelled to clarify is that it is an exploratory study, that the sampling has limitations, and that if certain expected results had not been produced it did not mean they do not exist, simply that we did not look for those precisely or that our sample had not experienced certain issues. Research can be frustrating in that sense, as it produces incomplete pictures of a certain situation and a need for more research.

### *Online analysis*

The analysis phase was the one that mostly resented the online work. The entire project was done remotely with both co-researcher groups and has worked smoothly. However, the phase of analysis was particularly hard to do online, especially with my co-researchers with learning disabilities. I think that, in this case, working in person makes it easier to introduce different exercises to lead the analysis, e.g. color coding, post-it exercises, playing with snippets of the interviews. Secondly, it would have been more comfortable to watch the recordings on a big screen and comment on it in a circle or in pairs, rather than over screen sharing (partly due to the small devices people had). Thirdly, it would also have been easier to ‘read the room’, which is much harder in online spaces (Strong et al., 2020).

### *My role*

Firstly, my role was to facilitate the analysis process as structured as possible, being flexible and creative to find different ways to engage with the data. In a second step, once we already had some ideas, I could more actively search for analysis of the data, and then to explore possible interpretations more directly, by questioning, or putting them in contrast with other interpretations or with the data. Lastly, in some instances, where I felt we had still missed some ideas, I would propose an interpretation or other themes in the form of questions.

This form of facilitation requires containment, which is not always easy but was integral to avoid taking over the space, especially with people who might have experienced being overly corrected by professionals, or in whose context it is always assumed the professional is right.

My aim was to maintain the thread of the conversation, by picking up our themes over several weeks, sometimes in more structured activities, sometimes by reflecting on my co-researchers’ own experience to make sense of the data, sometimes examining excerpts of the data or the text we had written. Ideally, the aim is to enjoy the process but at times it can be painful or unpleasant. Active listening is essential to link the conversations (including some of the informal spontaneous ones) occurring during our working sessions to our analysis.

The role of the researcher shifts throughout the project, but in this phase especially. At times, I was facilitating the conversation and the process, in other moments, I was more active in the analysis, depending on what I considered that would help the conversation.

### *Dissemination*

Some co-researchers thoroughly enjoyed the dissemination activities and engaging beyond their usual networks. There was an urge to engage in as many opportunities as possible, due to a perception of a lack of opportunities to meet people and engage in these types of discussions. During one of the feedback sessions on the project, people said they looked forward to engaging in more activities. However, in some instances, other panelists did not seem to recognize my

co-researchers as valid speakers. Gleitman talks about the denial of ‘speakerhood’ of persons with disabilities when others do not recognize them as communicators.<sup>3</sup>

In some instances, my co-researchers had to engage in awareness raising prior to being able to talk about the actual research, due to the gap in the knowledge about female autism or people with learning disabilities. On the one hand, it is great to be able to raise awareness and contextualize the research on the co-researchers’ terms, on the other, it takes time and attention from the research itself.

In this project, I experienced the dissemination activities as at least equally important as the research project itself. The weight of ensuring that my co-researchers led the dissemination efforts and engaged with other researchers and the wider public were more important to me than in other projects.

## Conclusion

Involvement in analysis and dissemination is essential and significantly shapes the outcome and impact of research. It is in this phase where most of the barriers and discrimination are identified and exposed. Participation means contributing to the conversation around knowledge production and involves exploring realities, understanding, making sense of the data collectively and individually. The phase of analysis is complex not only because it requires an effort of concentration, but it presents the limits of research and data, and it challenges our own worldviews.

The role of the researcher shifts during this phase and requires active listening to respond to the group’s changing needs, which at the same time creates learning opportunities and enriches the research process. Despite the challenges of the online format, we found different ways to make it work for all co-researchers and to include their views, experiences and reflections on the data. Dissemination has, in my experience, a higher impact when it is led by my co-researchers and allows for further networking and engagement with academia. Participatory human rights based research methodologies are particularly relevant to social policy, due to its impact on the shaping of the rights and realities of persons with disabilities and the complexities it addresses.

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## 7 Support for understanding criminal proceedings: the experiences of defendants with cognitive impairments in England

**Edmore Masendeke**

### Abstract

This research focuses on the support needs of defendants with cognitive impairments concerning their ability to follow or understand what is happening in court. Concerns have been raised regarding the effectiveness of the support measures which have been put in place for such defendants in England. However, there is a general lack of empirical research into the effectiveness of these support measures and little is known about the views and experiences of defendants with cognitive impairments. Therefore, this research was carried out to find out more about the experiences of defendants with cognitive impairments and the support that they received to help them understand what happens in court. Nine former defendants with mental health conditions, learning disabilities, autism or dyspraxia were interviewed for this research. The findings demonstrate the appropriateness of support provided to defendants to help them understand what was happening in court, and the consequences of not receiving this support. Those who had the support seem to have better understood what was happening in court than those who did not have it. Some of the participants believed that they did not receive the kind of support that they needed or sufficient support because of knowledge gaps, undiagnosed impairments and inequalities in statutory provisions. These findings suggest that there may be a need to raise awareness of cognitive impairments and associated support needs amongst legal professionals, non-legal support providers and court staff.

Keywords: cognitive impairment, understanding, defendant, court

### Introduction

This research focuses on the support needs of defendants with cognitive impairments concerning their ability to follow or understand what is happening in court. Research demonstrates that people with cognitive impairments may find it difficult to follow or understand what is happening in court due to disabling factors such as the complexity of the interviewer's questioning style, the language used in court and court procedures.<sup>1</sup> Recognising that appropriate support may reduce the impact of these potentially disabling factors on the

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<sup>1</sup> Louise Ellison, 'Cross-examination and the intermediary: Bridging the language divide?' (2002) *Criminal Law Review* 114; Janine Benedet and Isabel Grant, 'Taking the Stand: Access to Justice for Witnesses with Mental Disabilities in Sexual Assault Cases' (2012) 50(1) *Osgoode Hall Law Journal* 1; Alan Cusack, 'Victims of Crime with Intellectual Disabilities and Ireland's Adversarial Trial: Some Ontological, Procedural and Attitudinal Concerns' (2017) 68 *N Ir Legal Q* 433; Neta Ziv, 'Witnesses with mental disabilities: Accommodations and the search for truth' (2007) 27(4) *Disability Studies Quarterly* <<https://dsq-sds.org/article/view/51/51>> accessed 7 August 2021.

ability of people with cognitive impairments to follow or understand what is happening in court, the the English government has introduced several support measures in the criminal justice system over the past twenty years.

One such support measure allows courts to appoint a person to act as an intermediary between the witness and the court.<sup>2</sup> Before the court proceedings, intermediaries assess a witness's communication ability and support needs, then advise the court on how to question the witness.<sup>3</sup> They may also recommend other accommodations, including that the witness visits the court before the court proceedings.<sup>4</sup> They attend court proceedings with the witness and may intervene if the questioner asks a question that is too complicated for the witness to comprehend or if the witness's answer is unintelligible to the questioner.<sup>5</sup> Intermediaries may also support the witness by explaining the evidence given by other witnesses, court procedures, what is said by legal professionals, the verdict and the sentence.<sup>6</sup> However, defendants have reportedly found it difficult to access intermediaries as they were excluded from the original legal provisions for intermediaries.<sup>7</sup>

Subsequently, the Coroners and Justice Act 2009 made provisions for defendants to be supported by intermediaries, but these provisions are not yet in force.<sup>8</sup> Courts have sometimes used their inherent powers to appoint intermediaries for defendants in the interest of fairness.<sup>9</sup> However, this practice was restricted by a 2016 amendment to the Criminal Practice Directions<sup>10</sup> and by funding constraints.<sup>11</sup> In addition, intermediary services for defendants used to be unregulated. In April 2022, however, the government introduced a new intermediary scheme for defendants – the HMCTS Approved Intermediary Service (HAIS) – to standardise

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<sup>2</sup> Youth Justice and Criminal Evidence Act 1999, s 29.

<sup>3</sup> Ministry of Justice, *The registered intermediary procedural guidance manual* (Ministry of Justice 2015).

<sup>4</sup> Ministry of Justice, *The registered intermediary procedural guidance manual* (Ministry of Justice 2015).

<sup>5</sup> Penny Cooper and David Wurtzel, 'A Day Late and a Dollar Short: In Search of an Intermediary Scheme for Vulnerable Defendants in England and Wales' (2013) 1 Criminal Law Review 1.

<sup>6</sup> Ministry of Justice, *The registered intermediary procedural guidance manual* (Ministry of Justice 2015).

<sup>7</sup> Youth Justice and Criminal Evidence Act 1999, s 29

<sup>8</sup> Coroners and Justice Act 2009, s 104 inserted ss 33BA and 33BB into the Youth Justice and Criminal Evidence Act 1999.

<sup>9</sup> See *R v SH* [2003] EWCA Crim 1208; *R v Camberwell Green Youth Court* [2005] UKHL 4 [59] (Baroness Hale); and *C v Sevenoaks Youth Court* [2009] EWHC 3088 (Admin), [2010] 1 All E.R. 735 at [17].

<sup>10</sup> The 2016 amendment made to the Criminal Practice Directions specified that the appointment of an intermediary for a defendant for giving evidence in court will be 'rare' and for the entire trial will be 'extremely rare' (see Criminal Practice Directions 2022, pt 3F.13). This directive was confirmed in the 2017 case of *R v Rashid* [2017] EWCA Crim 2 [73]. Lord Justice Thomas stated that there 'may be rare cases where what [...] [is] required is an intermediary.'

<sup>11</sup> Samantha Fairclough, 'The consequences of unenthusiastic criminal justice reform: a special measures case study' (2021) 21(2) Criminology & Criminal Justice 151.

support for vulnerable court and tribunal users.<sup>12</sup> This initiative may improve defendants' access to intermediaries.

In the absence of intermediary assistance, there are other ways that courts can support defendants. For example, courts can allow a 'suitable supporting adult' – a family member or social worker – to sit next to a defendant throughout the proceedings<sup>13</sup> and, with the help of the defendant's legal representatives, explain to the defendant each step as it takes place and the possible consequences of a guilty verdict.<sup>14</sup> Thus, a 'suitable supporting adult' and the defendant's legal representatives may be expected to help defendants with cognitive impairments follow and understand what is happening in court. These support measures have been supplemented by training programmes and handbooks for legal professionals and court staff.<sup>15</sup>

However, several researchers have questioned the effectiveness of these support measures.<sup>16</sup> For instance, Owusu-Bempah has suggested that the defendant's legal representatives or 'supporting adults' may not be suitable substitutes for intermediaries because intermediaries, as communication specialists, can identify and address communication problems which other people might not be able to identify and address.<sup>17</sup> While such concerns have been raised in

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<sup>12</sup> Her Majesty Courts & Tribunals Service, 'Guidance: HMCTS intermediary services' (Her Majesty Courts & Tribunals Service, 1 April 2022) <<https://www.gov.uk/guidance/hmcts-intermediary-services>> accessed 28 July 2022.

<sup>13</sup> The Consolidated Criminal Practice Direction of October 2011, Pt III: Further Practice Directions Applying in The Crown Court and Magistrates' Courts — Criminal Procedure Rules, III.30.10, TREATMENT OF VULNERABLE DEFENDANTS <[http://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2011/ccpd-part-III-further-pds-applying-in-the\\_Crown-Court-and-magistrates-courts-oct2011.pdf](http://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2011/ccpd-part-III-further-pds-applying-in-the_Crown-Court-and-magistrates-courts-oct2011.pdf)> accessed 17 January 2021.

<sup>14</sup> The Consolidated Criminal Practice Direction of October 2011, Pt III: Further Practice Directions Applying in The Crown Court and Magistrates' Courts — Criminal Procedure Rules, III.30.11, TREATMENT OF VULNERABLE DEFENDANTS <[http://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2011/ccpd-part-III-further-pds-applying-in-the\\_Crown-Court-and-magistrates-courts-oct2011.pdf](http://www.justice.gov.uk/courts/procedure-rules/criminal/docs/2011/ccpd-part-III-further-pds-applying-in-the_Crown-Court-and-magistrates-courts-oct2011.pdf)> accessed 17 January 2021.

<sup>15</sup> For example, The Advocate's Gateway, 'The advocate's gateway toolkits' (The Advocate's Gateway, n.d.) <<https://www.theadvocatesgateway.org/toolkits-1-1-1>> accessed 28 July 2022; Royal College of Speech and Language Therapists 'The Box training' (Royal College of Speech and Language Therapists, 2018) <<https://www.rcsltcpd.org.uk/>> accessed 28 July 2022; Polly McConnell and Jenny Talbot, *Mental health and learning disabilities in the criminal courts: Information for magistrates, district judges and court staff* (Prison Reform Trust and Rethink Mental Illness 2013).

<sup>16</sup> See Abenaa Owusu-Bempah, 'Understanding the barriers to defendant participation in criminal proceedings in England and Wales' (2020) 40(4) *Legal Studies* 609; Penny Cooper and Michelle Mattison, 'Intermediaries, Vulnerable People and the Quality of Evidence: An International Comparison of Three Versions of the English Intermediary Model' (2017) 21 *International J. of Evidence and Proof* 351; Nigel Stone, 'Legal Commentary: Special Measures for Child Defendants: A Decade of Developments' (2010) 10(2) *Youth justice* 174.

<sup>17</sup> Abenaa Owusu-Bempah, 'Understanding the barriers to defendant participation in criminal proceedings in England and Wales' (2020) 40(4) *Legal Studies* 609.

existing literature, there is a general lack of empirical research into the effectiveness of the support measures and little is known about the views and experiences of defendants with cognitive impairments.<sup>18</sup>

This research aimed to understand the experiences of defendants with cognitive impairments and discover the support that they received to help them understand what happens in court. To this end, the following research questions were addressed:

1. How were people with cognitive impairments supported before, during and after court proceedings, and how did they benefit from this support?
2. What hindered people with cognitive impairments from getting the support they needed, and how well did they cope without this support?
3. What lessons can be drawn from these experiences and what are the implications for policy and practice?

### Methodology

The data presented in this chapter were collected in 2021 and 2022 as part of my PhD research. I initially conducted 2 one-to-one interviews, then later conducted a group interview with 7 former defendants who identified as having mental health conditions, learning disabilities, autism, dyspraxia or a combination of two or more of these impairments. Of the 9 participants, 7 were men and 2 were women, all adults. As other researchers have found it difficult to recruit participants with cognitive impairments for research,<sup>19</sup> I also found it difficult to recruit a sufficient number of participants who had recently been in court. Therefore, I recruited participants whose last court appearances were 2 to 30 before the interviews. Five of the participants’ cases were heard in both the Magistrates’ Court and the Crown Court, while 3 cases were heard in the Magistrates’ Court (see *Table 1* below). The participants’ names have been changed to protect their privacy.

*Table 1: Participants’ details*

| Participant’s name | Impairment(s)       | Gender | Last time in court | Type of court                      |
|--------------------|---------------------|--------|--------------------|------------------------------------|
| <b>Ben</b>         | Learning disability | Male   | 4 years            | Magistrates’ Court and Crown Court |

<sup>18</sup> Kim Turner and Nathan Hughes, ‘Supporting young people’s cognition and communication in the courtroom: A scoping review of current practices’ (2022) *Criminal Behaviour and Mental Health* 1.

<sup>19</sup> Nicholas Lennox and others, ‘Beating the barriers: recruitment of people with intellectual disability to participate in research’ (2005) 49(4) *Journal of Intellectual Disability Research* 296; Tessa Beckene, Rachel Forrester-Jones and Glynis H. Murphy, ‘Experiences of going to court: Witnesses with intellectual disabilities and their carers speak up’ (2020) 33(1) *Journal of Applied Research in Intellectual Disabilities* 67; Heather Becker and others, ‘Recruiting people with disabilities as research participants: challenges and strategies to address them’ (2004) 42(6) *Mental Retardation* 471.

|                |   |        |             |                                    |
|----------------|---|--------|-------------|------------------------------------|
| <b>Coco</b>    | Mental health conditions and autism spectrum disorder                 | Female | 11-13 years | Magistrates' Court and Crown Court |
| <b>Jim</b>     | Learning disability   | Male   | 20 years    | Magistrates' Court                 |
| <b>Kate</b>    | Mental health condition   | Female | 4 years     | Crown Court and Magistrates' Court |
| <b>Max</b>     | Mental health condition   | Male   | 2 years     | Magistrates' Court                 |
| <b>Mike</b>    | Learning disability, mental health conditions, dyslexia and dyspraxia | Male   | 25-30 years | Magistrates' Court                 |
| <b>Paul</b>    | Learning disability   | Male   | 30 years    | Crown Court and Magistrates' Court |
| <b>Sean</b>    | Autism spectrum disorder  | Male   | 20 years    | Magistrates' Court                 |
| <b>William</b> | Epilepsy, mental health conditions and learning disability            | Male   | 15 years    | Crown Court and Magistrates' Court |

Ethical approval was obtained from the University of Leeds Research Ethics Committee. All participants were informed about the research through an information sheet, which was also available in Easy Read format. Only those able to consent for themselves were included in this research. The one-to-one interviews were conducted on Microsoft Teams and lasted 40 and 60 minutes. The group interview was conducted in a conference room at a government office building and lasted for 1 hour and 15 minutes. Two people from a community support organisation attended the group interview and supported participants by repeating or explaining questions, providing prompts to facilitate recall of events and providing emotional support. The community support organisation had been directly involved in recruiting the participants. All interviews were audio recorded with prior consent from participants and were transcribed verbatim for subsequent thematic analysis following Braun and Clarke's approach.<sup>20</sup>

### Results and discussion

The results highlighted the appropriateness of the support defendants received to understand what was happening in court, and the consequences of not receiving this support. They also highlighted the factors which made it difficult for defendants to get the support that they need.

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<sup>20</sup> Virginia Braun and Victoria Clarke, 'Thematic analysis' in Harris Ed Cooper, Paul M. Camic, Debra L. Long, A. T. Panter, David Ed Rindskopf and Kenneth J. Sher (eds), *APA handbook of research methods in psychology: Research designs: Quantitative, qualitative, neuropsychological, and biological* (Vol 2, American Psychological Association 2012).

*Who received support? From whom? And when?*

Four of the nine participants, Ben, William, Coco and Max, indicated that they received support to help them understand what was going to happen, was happening or had happened in court. This support was provided before, during or after court proceedings. According to the participants, a solicitor, a support worker, a Queen's Counsel (QC), a mental health nurse or someone from the court variously explained what to expect, was happening or had happened during court proceedings. However, Coco indicated that her case had been heard in two different courts and she only received support before one of them, while William indicated that he had not been given the support that he needed in an earlier case. Both Coco and William discussed these experiences during the interview. Therefore, some of their responses appear to contradict each other, while in fact they represent their experiences at different courts or during different cases. Furthermore, Max only received support before court – a mental health nurse explained to him what was going to happen in court – but he had no support during and after court. Therefore, as discussed below, he did not understand what the legal professionals said in court and the outcome of his case, which were two of the difficulties which were faced by most of the five participants who indicated that they did not receive any support to help them understand what was happening in court.

It is apparent that the cases of those who received support were held 2 to 15 years before the interview, while the cases of those who did not receive support were held at 20 to 30 years before the interview, except Kate.<sup>21</sup> This is perhaps expected as it is within the last 20 years that above mentioned support measures, guidance, training programmes and handbooks for legal professionals and court staff were introduced in England. These developments have raised general awareness of the support needs of people with cognitive impairments in the justice system<sup>22</sup> and could be one of the reasons why the defendants whose cases were held 2 to 15 years before the interview received support to help them understand what was happening in court.

*The support which defendants found to be beneficial*

The defendants who received support generally felt that it was beneficial. Coco and William said that they benefited from being told what court looks like and what was going to happen during court proceedings. This included explaining the judge's role.

“I wasn't really shown how the design was, but I was just told how it works and that and what the design actually is.” – Coco

“I went to different courts. Um, one of them very easily ... It took me through what's the judge's role and that. Um. So, that was quite alright.” – Coco

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<sup>21</sup> Kate indicated that although she did not have support, she understood what was happening in court because she had attended law school for “only a few years.”

<sup>22</sup> Criminal Justice Joint Inspection, *Neurodiversity in the criminal justice system: A review of evidence* (Criminal Justice Joint Inspection 2021); Sheila Hardy and others, ‘Raising magistrates’ awareness of vulnerable adults: a pilot’ (2016) 20(4) *Mental Health Practice*.

Supporter 2: ... when you were in court, did you have anybody kind of always sitting with you and explaining what was happening? Did you know what to expect?

William: Yeah, yeah, I had my solicitor talking to me, my barrister, yeah.

Ben said that he benefited from having a support worker facilitating communication with his solicitor. The support worker explained what the solicitor was saying in a way that Ben understood.

“...if I didn't understand the solicitor properly, then ... he would ... try and ... put it in a way ...that I would understand of the solicitor because he ... this lady explained to her what he was trying to say to me.” – Ben

As the support worker did not have the right of audience in court, he also explained what was going to happen and what had happened both before and after court proceedings. Two recent studies on neurodiversity in the criminal justice system also found that participants appreciated the support which they had received from peers, advocates and others because it helped them understand what was happening.<sup>23</sup>

#### *The consequences of not receiving support*

Participants identified four consequences that they associated with not receiving this support. First, Sean indicated that he did not understand what was happening and the questions that he was asked during court proceedings because he did not understand the legal language that was used in court.

“I didn't understand what was happening. It was like I was in a daze; like I didn't really understand what ... what the questions were asking, and like what court is like, you know, I guess, how to get in ... I didn't understand like what the judge is saying or any questions that they are asking me, to be fair. It was just mumble jumbo. It is just like in a different language which, you know, I really didn't understand.” – Sean

Similarly, although a mental health nurse explained to him what was going to happen in court, Max said that he could not understand what the legal professionals were saying in court because he had no support during court proceedings.

“I was desperately trying to understand the conversations of the legal professionals, but I ... I did not understand. No, nothing was explained to me.” – Max

Max's experience was similar to Sean's experience in court because they both had no support and they could not understand the legal language that was used during court proceedings. Concerning this issue, Jim believed that since defendants did not always have this support during court proceedings, explaining what was going on in court was not beneficial to

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<sup>23</sup> User Voice, “*Neuro...what?*” *Neurodiversity in the criminal justice system* (User Voice 2021); Criminal Justice Joint Inspection, *Neurodiversity in the criminal justice system: A review of evidence* (Criminal Justice Joint Inspection 2021).

defendants with mental health conditions or learning disabilities because courts tended to use complex language. Max's experience in court might be seen as an example of this.

"The communication of legal courts ... people with learning disabilities, mental health issues, they don't understand them. That's the problem. And, trying to explain to somebody with mental health or learning difficulties what's going on in court is absolute rubbish. There is ... no (one) ... before the ... before the Court starts taking you in rooms, saying, 'Right. This is what's gonna happen. That's what's gonna happen. This is what the judge will say. This is what the barrister will say.'" – Jim

Second, Sean indicated that he was not even aware that he could be sentenced to prison, and only became aware of it on the day of the trial.

Supporter 2: Sean, did you ever understand that the reasons you were in court might lead to a prison sentence?

Sean: No, not really. Nothing was just like ... it was a just a letter basically ... and that was it ... nothing to explain or anything. So, the system... I must say it has changed but I still think the system needs improving.

Supporter 2: But the first time you thought you might go to prison, when was that?

Sean: That was on the day.

Supporter 2: That was on the day when you were...

Sean: Yeah.

Supporter 2: When you were sentenced.

Sean: Yeah.

Third, as I mentioned earlier, Max was unsure of the outcome of his case because nobody had explained it to him during and after the court proceedings. His solicitor only told him the outcome of the case, and explained it to him, several weeks after the trial.

"I was unsure whether I was acquitted, that is, a formal declaration that I was not guilty of the charges put in front of me. He (the solicitor) said 'No, I wasn't acquitted. The case was dropped.' So ... that ... that only came ... that was only explained to me weeks afterwards ...." – Max

Finally, Mike and Jim believed that not having support affected the outcomes of their cases. They believed that it landed them in prison or resulted in them being given long prison sentences.

"I'm pretty sure that I didn't get any support and there are many couple of times that I got slang slog into jail." – Mike

"And in court, I was never heard ... never got help ... and um ... I wish I had it because it probably made me spend a lot long in prison ..." – Jim

In summary, participants attributed difficulties in understanding what is happening in court, what was said in court or the possible outcome of the case to not having support in court. Two of the participants also believed that not having support affected the outcomes of their cases.

While there is empirical little research on defendants' courtroom experiences, O'Mahony found that the language the lawyer used in the courtroom was sometimes too complex for a defendant with a learning disability to understand.<sup>24</sup> These findings echo the longstanding position that people with cognitive impairments may be disadvantaged in understanding court proceedings if they appear in court without appropriate support.<sup>25</sup>

***Factors that made it difficult for defendants to get the support that they need***

Participants also spoke about difficulties in getting the support that they needed. They indicated three factors that made it difficult for them to get the support that they need. The first factor was a lack of an understanding of their support needs among courts and service providers.

“I didn't ... didn't ... didn't get the right ... the right support I needed it at the time ... um ... because the fault I had and all the support I needed from ... from my ... from [support provider organisation name], from [support provider's name], the person I was with, there was some confusion within what support I was getting.” – Ben

William suggested that one of the reasons why courts lack an understanding of their support needs is because they do not listen to them when they tell them their support needs.

“I even said to the judge, ‘You know, I don't understand what you're saying. You know, I've got epilepsy, my awareness disability.’ I said that.” – William

“The courts ... you know ... I don't think they listen.” – William

Interestingly, both Ben and William indicated that they had received support to help them understand what was happening in court. However, this may not be an unexpected finding because most of the support was provided before or after, but not during, the court proceedings. Therefore, it is not unexpected for them to have experienced difficulties in accessing the support that they needed during the court proceedings. In their 2021 research report, User Voice reported that no adjustments were made for defendants with neurodivergent conditions due to a lack of understanding of neurodivergent conditions.<sup>26</sup> Several researchers have also suggested that judges are reluctant to make further accommodations for defendants with cognitive impairments during court proceedings due to a lack of understanding of cognitive impairments.<sup>27</sup>

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<sup>24</sup> Brandon M O'Mahony, 'Accused of murder: supporting the communication needs of a vulnerable defendant at court and at the police station' (2012) 3(2) Journal of Learning Disabilities and Offending Behaviour 77.

<sup>25</sup> Abigail Gray, Suzie Forell, and Sophie Clarke, 'Cognitive impairment, legal need and access to justice' (2009) 10 Justice Issues 1; Kristine I Ericson and Nitza B Perlman, 'Knowledge of Legal Terminology and Court Proceedings in Adults with Developmental Disabilities' (2001) 25 Law Hum Behav 529; David Bean and others, *Unfitness to Plead* (Volume 1, Law Commission 2016).

<sup>26</sup> User Voice, "Neuro...what?" *Neurodiversity in the criminal justice system* (User Voice 2021)

<sup>27</sup> Brandon M O'Mahony, 'Accused of murder: supporting the communication needs of a vulnerable defendant at court and at the police station' (2012) 3(2) Journal of Learning Disabilities and Offending Behaviour 77; David Bean and others, *Unfitness to Plead* (Volume 1, Law Commission 2016).

The second factor was having no diagnosis of the defendant's impairment. Paul felt that he was not given the support that he needed because his impairment had not been diagnosed when he went to court.

“At the time ... the time I got nothing. I don't think I got any help because I've got autism. I didn't get diagnosed that so you've got.” – Paul

The final factor was the inequality of treatment between defendants and complainants. In the same case, Ben had been interviewed as a complainant and as a defendant. He was assisted by an intermediary when he was interviewed as a complainant at the police station but was not given the same support when he was interviewed as a defendant. Thus, Ben felt that it was more difficult to get support when you are a defendant than when you are a complainant.

“It not as easily available if you are a defendant, but if you're a victim, you get more help if you're a victim, but not as the defendant.” – Ben

To Ben, it also appeared as though the rules change when you are a defendant and said that they should not change.

“But the rules ... rules ... the rules change when you're a defendant but when you're a victim then the rules change again. So, the rules shouldn't change if you're ... when you're the defendant it should be the same as you are a victim ... but you're not.” – Ben

The disparity between witnesses' and defendants' access to an intermediary has been widely criticised in existing literature.<sup>28</sup> The above finding reinforces the need to address this disparity. While the introduction of the HAIS may in some ways do so, it is still early days to evaluate the scheme's effectiveness.

## Conclusion

This chapter demonstrates tentative evidence for the benefits of providing defendants with cognitive impairments support for understanding what is happening in court. Hitherto, there has been very little empirical research on the effectiveness of the support measures that courts are expected to rely on in the absence of intermediary assistance and defendants with cognitive impairments' views and opinions of that experience. The findings of this research suggest that those who received the support found it beneficial, while those who did not receive this support found it difficult to follow and understand what was happening during court proceedings.

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<sup>28</sup> See for example Laura Hoyano, 'Coroners and Justice Act 2009 – Special Measures Directions Take Two: Entrenching Unequal Access to Justice?' (2010) *Criminal Law Review* 345; Jenny Talbot, *Fair access to justice? Support for vulnerable defendants in the criminal courts* (Prison Reform Trust 2012).; Laura Hoyano and Angela Rafferty, 'Rationing defence intermediaries under the April 2016 criminal practice direction' (2017) 2 *Criminal Law Review* 93; Samantha Fairclough, 'Speaking up for Injustice: Reconsidering the provision of special measures through the lens of equality' (2018) 1 *Criminal Law Review* 4.

However, some of the defendants who had support experienced the same difficulties that were experienced by those who did not have the support. This may be attributed to the fact that most of the support providers could only support the individual before or after, but not during, court proceedings.

It should be noted that this sample cannot be taken as a representative sample of persons with cognitive impairments in similar situations. The sample size was small and not all the defendants have recent experience. Notwithstanding the latter point, this research demonstrates that some longstanding problems have not yet been addressed since some participants experienced these problems regardless of how long ago they went to court. Perhaps, what may be more surprising is the fact that similar issues have been raised in recent research involving larger sample sizes.<sup>29</sup> This bears testimony to the relevance of this research. In view of this, this research recognises that there may be a need to raise awareness of cognitive impairments and associated support needs amongst legal professionals, non-legal support providers and court staff.

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<sup>29</sup> User Voice, “*Neuro...what?*” *Neurodiversity in the criminal justice system* (User Voice 2021); Criminal Justice Joint Inspection, *Neurodiversity in the criminal justice system: A review of evidence* (Criminal Justice Joint Inspection 2021).

## 8 From policy commitments to practice: do persons with disabilities participate in EU funded development programs in Mozambique?

**Jorge Manhique**

### Abstract

What EU development policies and programs tell us about their commitment to inclusion and participation of person with disabilities? What effect these policies and programs have on the ability of persons with disabilities to participate in the formulation and implementation of development programs? This chapter maps and review policy and program documents, guidance and operational tools adopted by the EU to fulfil their obligation under article 32 of the CRPD. The chapter focus on how these entities have incorporated their obligations under the CRPD, as well as the effectiveness and shortcomings of their approach in relation to inclusion and participation of person with disabilities. The paper also draws from the perspective of key stakeholders - through semi-structured interviews and focus group discussions - involved in the implementation of two EU funded programs. The two programs are implemented by a network of UN agencies and local Civil Society Organizations in Mozambique. Despite policy pledge and guidelines put in place by the EU, persons with disabilities are not yet fully included in the formulation and implementation of development programs. There is discrepancy between EU policy documents that promote disability inclusion in external action and person with disabilities perception of participation, development.

### Effort to promote human rights and development in EU external action

Preoccupation with human rights, participation and respect for human dignity is central to the EU project both internally and globally. Title V of the Treaty of the European Union (Treaty of the EU, 2012) establishes the principles and objective of the Union in relation to the Union's External Action, which include international development cooperation. In this regard article 21 states that EU action on the international stage shall be informed by the principles of 'democracy, the rule of law, the universality and indivisibility of human rights and fundamental freedoms, respect for human dignity, the principles of equality and solidarity, and respect for the principles of the United Nations Charter and international law', values which have informed the Union creation and its expansion (Treaty of the EU, 2012 p. 28. Article 31). In the same vein establishes as objective, among others, work to 'consolidate and support democracy, the rule of law, human rights and the principles of international law', (TEU, article 21 para. 2.b). The Treaty puts emphasis on the need to promote multilateralism and to work within the framework of the United Nation to achieve the stated objectives (Treaty of the EU, 2012).

The Treaty of the Function of the EU (TFEU) reinforces the stated in the chapter V of the TEU, and indicates that the 'Union development cooperation policy shall have as its primary objective the reduction and, in the long term, the eradication of poverty' (TFEU, 2012, article 208). Moreover, when pursuing its development policy, the TFEU states that the 'Union and the Member States shall comply with the commitments and take account of the objectives they have approved in the context of the United Nations...' (TFEU, 2012, title III, article 208.2).

The European Consensus on Development which represent the 'cornerstone of the EU development policy' details a list of principles and values guiding development action (those listed in the TEU). Further the EU and Member States commit to implement a rights-based approach to development cooperation, encompassing all human rights (EU Consensus on

Development 2017, para. 16). Critically, the EU and Member states ‘value the participation of civil society organizations (CSOs) in development and encourage all parts of society to actively engage’ (EU Consensus on Development 2017, para. 17). Finally, the EU and its Member States commit to apply development effectiveness principles, namely: ‘ownership of development priorities by developing countries, a focus on results, inclusive development partnerships, transparency, and mutual accountability’ (EU Consensus on Development 2017, para. 18). Notably, the EU and Member States identify the Political Dialogue as critical forum to advance ‘development principles’ but also to review progress and identify areas of support to partner countries (EU Consensus on Development 2017, para. 14).

The New European Consensus on Development, which is part of the overall EU response to the 2030 Agenda, set four areas of actions: People — Human development and dignity; Planet — Protecting the environment, managing natural resources, and tackling climate change; Prosperity — Inclusive and sustainable growth and jobs; and Peace — Peaceful and inclusive societies, democracy, effective and accountable institutions, rule of law and human rights for all (European Commission 2017). Its primary objective is to pursue the objective of EU Development Policy which is to reduce and ultimately eradicate poverty.

The EU Consensus on Development recognize persons with disabilities and the fact that they are marginalized and commit to consider their needs in development cooperation in line with the CRPD to ensure their ‘full inclusion in society and equal participation in the labour market’ (EU Consensus on Development 2017, para 29 & 30). However, it does not say how, or which measure will be taken, as it does with youth and gender equality. It also fails to recognize that children, girls and women, and youth with disabilities are particularly vulnerable and therefore specific action need to be taken to protect them and ensure that they benefit from development outcomes. Moreover, disability is not explicitly considered as cross cutting issue as youth and gender among others (EC 2017, para 20). Finally, disability or persons with disabilities are only referred to in the first pillar of action ‘People — Human development and dignity’; while in other areas there is only reference to the term ‘vulnerable population’, which include those with disabilities. The conflation of disability under vulnerable population, may obscure the needs of people with disabilities in policy design and implementation.

The European Disability Strategy (EDS 2021 – 2030) which was adopted in 2021 represent the main tool that the European Commission has to implement the CRPD. The EDS 2021 – 2030, was adopted following the evaluation of its successor - the EU Disability Strategy 2010 – 2020. The EDS 2010-2020 was the first to be adopted after the ratification of the CRPD by the EU and had set eight areas of action, namely: i) Accessibility; ii) Participation; iii) Equality; iv) Employment; v) Education and Training; vi) Health; vii) Social Protection; and viii) External Action. In addition, the Strategy set a framework for implementation which include Awareness Raising; Financial Support; Statistic and Data Collection and Monitoring mechanism Required by the CRPD (European Commission, 2010).

The evaluation of the 2010-2020 EDS found that it ‘contributed to promote the rights of persons with disabilities within the EU external action’ (European Commission, 2020, p. 33). However, the evaluation noted that the objective set for in External Action was ‘partially achieved because only two of the eleven actions of the Strategy were fully implemented, and all other actions were partially implemented’ (European Commission, 2020, p. 33). The evaluation noted that the ‘shortcoming in the field of External Action is related to the lack of indicators

for planning and monitoring interventions with specific reference to disability’ (European Commission, p. 34).

In 2014, the CRPD Committee reviewed the EU implementation of the CRPD, under the article 35. In the concluding observation, the CRPD Committee expressed concern with ‘the lack of a systematic and institutionalized approach to mainstream the rights of persons with disabilities across all European Union international cooperation policies and programs. The Committee also noted the lack of coordination and coherence among European Union institutions and the lack of disability focal points. It is also concerned that European Union international development funding is used to create or renovate institutional settings for the placement of persons with disabilities, segregated special education schools and sheltered workshops, contrary to the principles and provisions of the Convention’ (CRPD Committee, 2015, para. 75.p10).

Through the new Strategy 2020 – 2030, the Commission attempts to address some of these issues – raised on its own evaluation and CRPD Committees views - while also consolidating the gains of the previous Strategy. With this new Strategy, the EU intends to ‘reinforce its role globally as an advocate for rights of persons with disabilities’ (EU Disability Strategy, 2021, p.23). The Strategy serves an ‘inspiration to guide reform efforts and planning of assistance with partner countries and relevant stakeholders’ (EU Disability Strategy, 2021, p.23).

The strategy stresses that it is ‘is essential that external action respects and implements the CRPD principles alongside the agenda 2030’ (EU Disability Strategy, 2021, p. 24). In this Strategy, the EU commits to adopt a twin track approach to disability consisting of ‘targeted action on disability as well as disability mainstreaming in its external action’ (EU Disability Strategy, 2021, p. 24). The Strategy combines several approaches which include inward (within the EU processes) and outward actions (in support to partner countries and other relevant actors). In this connection, the Strategy plan to support ratification of the CRPD in partner countries that have not ratified; draft guidance documents to ‘implement accessibility and ensure meaningful consultation of persons with disabilities’ (EU Disability Strategy, 2021, p. 24). Critically, the Strategy commits to improve data collection on persons with disabilities in EU-funded programs using international recognized standards such as the Washington Short Set Questions, and support capacity building of civil society to ensure their needs are adequately addressed international development programs. Crucial in this strategy, is the role of EU delegations in partner countries. In this sense, the Strategy envisages that delegations should play supportive role ‘to advance the rights of persons with disabilities’ (EU Disability Strategy, 2021 p. 24). The EU commits to use a range of tools at its disposal, to advance the rights of person with disabilities, ranging ‘from political, human rights and trade’ dialogues (EU Disability Strategy, 2021, p. 24).

To complement these policy documents, the Commission's Directorate - General for International Cooperation and Development (DG DEVCO) drafted the Guidance Note for EU Staff on Disability Inclusive Development Cooperation. The guidance note ‘seeks to raise awareness of the issues (disability rights) among staff working on EU development cooperation at headquarters and in delegations and provide some general guidance on including people with disabilities in development processes’ (EuropAid, 2012 p.2). It is informed by the CRPD and was drafted after a review on disability inclusion in international development cooperation conducted by the Commission. The DG DEVCO proposed the following guidance principles:

- ‘Adopt and advocate the human rights approach to disability.
- Gather country-based analysis of the situation of people with disabilities and incorporate it in country poverty assessments.
- Pursue a twin-track approach in support of the implementation of the CRPD
- Promote and enable active participation and contributions by disabled peoples’ organizations (DPOs) and disability-focused organizations.
- Promote accessibility and ensure that EU-funded programs and services are accessible.
- Promote donor coordination and multi-stakeholder partnerships.
- Raise awareness and reinforce communication strategies’ (EuropAid, 2012).

Likewise, in 2019 the Council of the European Union adopted the EU Human Rights Guidelines on Non – Discrimination in External Action. The Guide include instructions on how to address disability-based discrimination in bilateral cooperation and dialogue; the EU Development Cooperation and Humanitarian Assistance; multilateral cooperation; and supporting efforts by civil society (Council of the European Union, 2019).

The Organization for Economic Cooperation and Development (OECD) approved, in 2018, the Disability Marker. The Disability Marker which was drafted at the initiative of United Kingdom, had the support of the EU (OECD, 2018). The Objective of the disability marker is to ‘contribute to mainstreaming disability issues into development cooperation activities, raising the awareness in the public debate and providing a comprehensive dataset for analysis’ (OECD, 2018). The Disability Marker is seen as crucial tool to increase mainstreaming of disability within international development cooperation and to ensure accountability and systematic monitoring of disability inclusive development initiatives (OECD, 2018). In this sense, it is an important operational instrument to support EU delegations and other development agencies. Although the new Disability Strategy commits to adopt the disability marker, it is not clear how will this be rolled out in the domain of external action, and it remains to be seen how delegation around the world will ensure that it is used in consistent and systematic way across programs and projects.

Another relevant document is the Cotonou Agreement. Signed in 2000, the Cotonou Agreement is an economic partnership between the EU and the group of African, Caribbean and Pacific States (ACP). The partnership aim to ‘promote and expedite the economic, cultural and social development of the ACP States, with a view to contributing to peace and security and to promoting a stable and democratic political environment’ (Cotonou Agreement, 2010, p.14). The agreement focus is on ‘reducing and eventually eradicating poverty consistent with the objectives of sustainable development and the gradual integration of the ACP countries into the world economy’ (Cotonou Agreement, 2010, p.14). Participation is one of the fundamental principles of Cotonou Agreement. It’s states that ‘apart from central government as the main partner, the partnership shall be open to ACP parliaments, and local authorities in ACP States and different kinds of other actors in order to encourage the integration of all sections of society, including the private sector and civil society organisations, into the mainstream of political, economic and social life’ (Cotonou Agreement, 2010, p.17).

At a country level the EU Delegation in Mozambique approved in 2021 its new Multi-annual Indicative Programme (MIP) 2021-2027. The MIP is a programmatic document developed by

the EU Delegations setting priority areas, specific objectives, indicators, and financial allocation for each recipient country. The Mozambican MIP 2021-2027 states that the principle of ‘Leaving No One Behind’ will guide EU’s interventions ensuring that people that are often excluded or marginalised, such as persons with disabilities..., can meaningfully participate in the implementation of the Program and ‘equally benefit from EU support’ (EU MIP, 2021, p.4). Moreover, the EU commits that all actions related with person with disabilities will be in line with the CRPD (EU MIP, 2021, p. 7). The EU further, commits to support civil society organizations to implement actions ‘to protect the rights of women, children, LGBTI persons, persons with disabilities, to promote freedom of thought, and to fight discrimination’ (EU Delegation Mozambique, 2021, p. 21). Critically, the EU commits to adopt ‘reasonable accommodation measures to ensure accessibility for persons with disabilities’ (EU MIP, 2021, p. 26).

In contrast with the commitments mentioned above, the MIP don’t have explicitly indicators on disability across all the three priority areas set in the Program. While there are specific indicators - and budget - on gender, youth and even on people living in rural areas – specifically in relation to priority area 2 - the Plan is silent when it comes to indicators on disability. To make things worse, there is no plan to disaggregate data on disability – reference is only made in relation to sex and age group. There is no reference, in the indicative Programme, of the EU Disability Strategy 2021-2030 which Delegations are expected to play a significant role in its implementation. In this context, it is hard to see how the commitment to ‘leave no one behind’ will be translated into practice through EU support in Mozambique.

### Participation of persons with disabilities in EU funded development programs

This section presents findings from interviews and focus group discussion with persons with disabilities directly and indirectly involved in two EU funded projects in the domain of gender-based violence and social protection.

The first project, Spotlight Initiative, is a multiyear program covering 28 countries across five regions of the globe. Mozambique is one of the beneficiary countries in the African region. The focus of the program varies across the region. The African program focus on ‘sexual and gender-based violence (SGBV), early marriage (with linkages to the eradication of harmful practices) and sexual and reproductive health rights (SRHR)’. The program is implemented by five UN Agencies in collaboration with Government Agencies and Civil Society Organizations (CSO). The second Project, *Monitoria Comunitária Independente (MCI) ao Programa de Subsídio Social Básico (PSSB)* is a five-year (2018 – 2023) project implemented by a consortium led by *Plataforma da Sociedade Civil Moçambicana para Protecção Social (PSCM-PS)*. The objective of the project is to improve the quality and impact of social protection programs and promote their transparency through awareness raising, access to information and active citizen participation in the accountability of social protection programs, with emphasis on the PSSB. The project has three interrelated components: i) Citizen Report: where beneficiaries of PSSB express their views of how the program is being implemented; ii) Focal Groups: where the main concern raised by citizens are discussed among them; and iii) Action plan: which consist of discussion forums where citizen’s concerns are presented to local leaders and service providers. With funding of 2.500.000,00 euros from the EU through the Support Program of Non-State Actors (PANNE II), the project is implemented in 6 provinces and a total of 10 districts.

This chapter investigates what effect EU policies on external action have on the ability of persons with disabilities to participate in the formulation and implementation of development programs using those presented above as reference. Interviews and focus group discussion were conducted with person with disabilities and other relevant stakeholders.<sup>30</sup> Person with disabilities were asked to reflect, among others, on the concept of participation and what it means for them, in practice, to participate in the community.

From the analysis of person with disabilities responses, the following themes are identified: i) access to information; ii) relevance of issues being discussed; iii) the value/respect towards person with disabilities; iv) participation involves difficult choices. For this paper these themes are called determinants of participation as the fulfilment, or not, of one of them may compromise the ability of persons with disabilities to participate in the formulation and implementation of development programs.

### Determinants of participation

i) **access to information** is determinant to meaningful inclusion and participation of any group more so for person with disabilities that experience high levels of stigma and discrimination. CRPD article 21 (Freedom of expression and opinion, and access to information) specifically calls upon State parties to ensure the right to “...*seek, receive and impart information and ideas on an equal basis with others...*”. Persons with disabilities that participated in this study revealed that critical to their participation is access to information, that is, an invitation to participate and conditions for that participation. Linked to this, is ii) **the issue being discussed** which as pointed out by participants must be of interest/relevance to them. This later point resonates with CRPD article 4.3, which call upon State parties to “*consult with and actively involve persons with disabilities*” in the implementation of the Convention and “*in other decision-making processes concerning issues relating to persons with disabilities*”.

### *iii) the value/respect toward person with disabilities*

According to persons with disabilities being valued and respected by the community is determinant to ensure their inclusion and participation. Respect and value, according to participants with disabilities, is linked to trust and responsibility and means that they are able and capable to fulfil social roles in the community. This speaks with CRPD article 8 (awareness raising) which call upon State parties to “*raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for [their] rights and dignity*”. While the EU policy documents commit to advance the implementation of the CRPD, there is no indicators and mechanism built in those programs to operationalize these intentions (Manhique, 2021).

### *iv) participation involves choices*

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<sup>30</sup> For this paper only interviews and focus groups discussion with person with disabilities was reviewed.

Participation for persons with disabilities involve difficult choices especially for women with disabilities and those without but with children with disabilities. In Mozambique, poverty impacts disproportionately women with disabilities and because of this burden, women with disabilities have to make difficult decision whether to participate in community meetings or go to field to grow crops or other activity that would give something to feed their families. A woman with disabilities said:

“I have to make a big sacrifice to have food. If I had someone [partner] to help me, maybe things would be different. As I am alone, I have to work my own field and that of others to get something to eat.”

In this context, participation is not only about access to information and relevance of issues discussed for persons with disabilities, but it is determined mainly by pragmatic choices. Incentives to participate, then became an important element in the equation. However, these incentives are not built in EU funded development projects under review. Even support and reasonable accommodation which are meant to ensure equal opportunities for persons with disabilities, are done on ad hoc basis.

### **Concluding remarks**

The EU policy documents on external action do consider disability as an important aspect of development cooperation and has made the promotion of human rights and dignity for all an integral part of their development policy. However, there is discrepancy between EU policy documents that promote disability inclusion in external action, the practice of inclusive development and person with disabilities perception of participation. EU policy documents and strategies reviewed in this paper, fall short of the standards set in the CRPD. There is limited description of how to do disability inclusion in practice, and how the greatest development problems that the EU intend to tackle (climate change, inequality, etc.), are related or impact person with disabilities, and how the proposed solution will improve their well-being. Without clear articulation of these development problems, with the needs of persons with disabilities it will be difficult to make the discussion of these issues relevant for persons with disabilities.

On a positive note, by embracing ‘rights-based approach to development’ the EU approach seem to go beyond the set of codified rights (UN Conventions). This is important, as it opens channels for communities in recipient countries to engage critically with human rights framework by promoting their idea of rights, values, norms, and living experience (Ife & Tascon, 2016).

While the new EU Disability Strategy seem to be progressive, there are aspects of it that are not clear how will they be rolled out. For instance, while through the Strategy the Commission commits to implement the Disability Marker, it is not clear how will this be rolled out and ensure that it is used in consistent and systematic way across programs and projects. Perhaps, it is because of this that some delegation continues to do business as usual. Finally, the 2021 - 2027 Multiannual Indicative Program for Mozambique, don’t make any reference to the EU Disability Strategy. This is troubling because EU Delegations are expected to play significant role in the implementation of the Strategy. Consequently, it is not clear how will the EU Delegation role out the Disability Strategy in Mozambique.

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## 9 Accessible voting materials so that persons with disabilities can effectively vote

**Adriana Caballero-Pérez, Maastricht University**

### Abstract

The study ‘Voting Matters’ explores the *de facto* realisation of the right to vote by persons with disabilities, or the ‘opportunity’ to enjoy this right on an equal basis with others. It examines the link between the provision and use of electoral-assistive devices (e.g., easy-to-read voter education guides) by voters with disabilities and positive obligations of States Parties under Article 29(a) CRPD. This study contributes to research in the field of political participation of persons with disabilities and has led to key findings: the use of assistive technology in elections is one measure for achieving greater accessibility in the voting environment; anti-discrimination prohibitions applicable in the context of voting are only effective when linked with equality measures, such as providing electoral-assistive devices, that remove inaccessible realities from within the voting environment; implementation of Article 29(a) CRPD can be enhanced or constrained not only by national legislation and policy instruments, but also by *practices* of relevant social actors; and addressing the legal and policy lacunae, as well as the *practices* within national electoral systems would have a substantive impact on the effective implementation of Article 29(a) CRPD in England and Spain.

### Introduction

Voting independently and secretly is a well-established principle and a necessary element for maintaining democratic integrity.<sup>1</sup> International human rights law, and particularly Article 29(a) of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006), has enumerated the right to vote of persons with disabilities on an equal basis with others. This provision sets out the obligation for States Parties to ensure that all persons with disabilities can effectively exercise a secret and independent ballot through, among others, positive measures, such as the provision of assistive devices and new technologies.

The study ‘Voting Matters’ adopts an evidence-based approach and a mixed-research design to explore the provision and use of assistive devices by voters with disabilities. It argues that providing such devices, and particularly electoral-assistive devices<sup>2</sup>, e.g., magnifiers, easy-to-read voter education materials or tactile ballot guides, is a measure for achieving greater accessibility in the voting environment (where appropriate). The results of this study are primarily focused on England and Spain (at the national level).

This study used an evidence-based approach. A small sample of persons with disabilities and election officials were research participants. They took part in online-interviews (including focus groups and individual interviews) and contributed to the results of this study by sharing their experiences in using existing electoral-assistive devices. The results discussed in this

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<sup>1</sup> Lionel E Fredman, *The Australian Ballot: The Story of an American Reform* (Michigan State University Press 1968).

<sup>2</sup> This study uses the term ‘electoral-assistive devices’ to refer to assistive devices provided to persons with disabilities in the context of voting by national electoral authorities.

study are based on data collected from 42 research participants in total. Therefore, the research findings cannot be generalised. The key findings of the study ‘Voting Matters’ are briefly explained in this paper below.

### Using assistive technology devices in elections is a concrete positive measure

The first set of findings arising from the study ‘Voting Matters’ relate to a non-exhaustive inventory of available and emerging electoral-assistive devices used in elections to assist persons with disabilities in performing electoral-related activities, such as voter registration and casting ballots. This study demonstrated that the use of assistive technology in elections is one measure for achieving greater accessibility in the voting environment.

The study is pioneering in that it identifies available and emerging electoral-assistive devices that can be used to assist voters with disabilities throughout the electoral cycle. The study provided a conceptual framework and illustrative examples of electoral-assistive devices that can be used to assist persons with disabilities when voting. Findings were based on a scoping review protocol designed to identify relevant literature and to carry out a comprehensive inventory and analysis of the devices. Based on the research carried out for this study, available devices were divided into six main groups: (i) haptic aids; (ii) reading aids; (iii) writing aids; (iv) visual aids; (v) electronic voting aids; and (vi) other communication aids. Emerging electoral-assistive devices were broadly divided into two groups: (i) haptic technology and (ii) other electronic technology.

Four main findings were drawn from the inventory. Firstly, States can provide voters with disabilities with diverse devices to assist them throughout the electoral process, meaning not only when casting ballots at polling stations. Secondly, electoral-assistive devices can be used by multiple groups of voters, including persons with disabilities and language learners. Thirdly, available electoral-assistive devices range from low-tech to high-tech devices or systems. This means that States can make available mechanical (i.e., manually operated) and affordable devices, as well as power source (i.e., electrically operated) and expensive devices to be used by voters with disabilities. Fourthly, the use of electoral-assistive devices by persons with disabilities involves procurement, security, and socio-cultural challenges for States.

### States Parties to the CRPD must adopt substantive positive measures to ensure the *de facto* realisation of the right to vote by persons with disabilities

The second set of findings arising from the study ‘Voting Matters’ involved a comprehensive legal interpretation of the obligations of States Parties pertaining to the provision of electoral-assistive devices to be used by persons with disabilities to vote under international human rights law, and primarily Article 29(a) CRPD.

Article 29(a) CRPD endorses the principle of *equality of opportunity*. It goes beyond a formal recognition of equality to address barriers to participation encountered by voters with disabilities. Pursuant to Article 29(a) CRPD, States Parties must address historical and persistent discriminatory barriers which hinder *de facto* equality of voters with disabilities. This reflects the substantive equality approach. States Parties also have the legal duty to adopt positive (active) measures to prevent and eliminate discriminatory practices and all systematic structural inequalities which hinder the participation and inclusion of voters with disabilities in elections. This reflects the transformative equality approach. Article 29(a) CRPD provides, therefore, that anti-discrimination provisions regarding voting are only effective when linked

with measures to achieve *de facto* equality, including the removal of inaccessible realities within the voting environment.

The research carried out for this study demonstrated that making electoral-assistive devices available to voters with disabilities throughout the electoral cycle is a measure related to the principle of *equality of opportunity*. Making such devices available is a positive measure which contributes to achieving greater accessibility in the voting environment [Article 29(a)(i) CRPD]; protects the right of persons with disabilities to vote secretly and independently [Article 29(a)(ii) CRPD]; and guarantees the free expression of the will of persons with disabilities as voters [Article 29(a)(iii) CRPD]. The research carried out for this study probed the link between implementing these obligations and providing electoral-assistive devices to be used by voters with disabilities. As noted, States Parties are also required to adopt other substantive positive measures to ensure the *de facto* realisation of the right to vote by persons with disabilities, including by establishing an obligation to provide reasonable accommodations to individual voters (Article 5 CRPD) and to apply universal design in the voting environment (Article 4 CRPD). All these positive measures must be consistent with the fundamental norms of non-discrimination and equality under the CRPD.

### **Compliance with Article 29(a) CRPD through law and policy, as well as in practice**

The third set of findings arising from the study ‘Voting Matters’ are based on a comprehensive analysis of compliance with Article 29(a) CRPD by England and Spain. The analysis covers compliance through law and policy, as well as in practice, with the latter research based on the voting experiences of research participants. In doing so, this study moves from law in books to investigate law-in-action, and mainly the ‘CRPD-in-action’. It analysed how Article 29(a) CRPD has been implemented through both law and policy, and ‘in practice’, in England and Spain. The study demonstrated that implementation of Article 29(a) CRPD can be enhanced or constrained not only by national legislation and policy instruments, but also by practices of relevant social actors as briefly examined below.

#### ***Compliance with Article 29(a) CRPD by England***

The CRPD has not been incorporated into the legal order of the UK. This means that voters with disabilities cannot rely on Article 29(a) CRPD directly, or a domestic law incorporating the Convention, to assert their right to vote. Instead, domestic law determines the right of voters with disabilities to vote. In the study ‘Voting Matters’, the compliance by England with Article 29(a) CRPD was primarily assessed through a comprehensive analysis of the consistency between relevant legislation and policy and the CRPD. As mentioned above, this study also explored experiences with using electoral-assistive devices of 13 voters with disabilities and 7 election officials from England, to ascertain how relevant national legal and policy instruments are implemented in practice.

In England voters with visual impairments are provided with three electoral-assistive devices on election day: an enlarged ballot paper copy (poster), a tactile voting device (TVD), and a hand-held large ballot paper copy (recently implemented). Overall, research participants who used the poster and TVD to help them vote considered the legal requirement (Rule 29 of Schedule 1 of RPA 1983) to make these devices available an important ‘*authoritative resource*’ that respects their inherent dignity and worth as human beings. This is an important finding, and confirms that adopting legislation to implement Article 29(a)(i) CRPD is an appropriate step to promote respect for the inherent dignity of voters with disabilities and improve their

voting experience. Nevertheless, other participants who could have used the existing devices to vote did not know anything about their right to use such devices or the availability of the devices. Accordingly, it was noted that appropriate voter education for voters with disabilities is necessary in England to foster respect for their agency. This concerns a duty which falls on the State under a transformative equality model, as endorsed in the CRPD.

This study revealed that participants who had used the electoral-assistive devices mentioned above sometimes encountered practices at polling stations which hampered them from effectively using these devices. One example of such practices is attitudes adopted by some election officials, and particularly their perceived pity towards voters with disabilities, as referred to by one participant. Another barrier is linked to improper positioning of the poster within polling stations and technical faults with the design of the TVD. This finding is underlined by the fact that England has not developed accessibility standards to follow when issuing voting materials and setting out the layout of polling stations, as well as when providing electoral-assistive devices.

Technical problems exist with the design and implementation of the poster and the TVD. These problems meant that most research participants who had used these devices had to ask for help and reveal their political choice to others in order to mark their ballots. Not all of these participants felt comfortable asking for help from others to vote. In such situations, the participants could not exercise their right to ballot secrecy as provided by Article 29(a)(ii) CRPD. This is an important finding that confirms that providing electoral-assistive devices without establishing any mechanism to examine their application (i.e., evaluating how devices are used and what substantial results they produce), is not an effective means to ensure the enjoyment of the right to ballot secrecy by voters with disabilities. Compliance with Article 29(a)(ii) CRPD requires regular monitoring and assessment of the progress made in ensuring ballot secrecy and independence through the implementation of electoral-assistive devices.

Overall, the examination of the experiences of the users of the poster and TVD, who took part in this study, demonstrated that these devices are not effectively addressing accessibility barriers to participate in elections by voters with visual impairments, as required by Article 29(a)(i) CRPD. Moreover, England has not provided proper training for election officials in, *inter alia*, the rights and needs of persons with disabilities, as well as training them in practical skills to assist voters with disabilities when using the existing electoral-assistive devices. These measures are fundamental to fully comply with Article 29(a) CRPD. The research carried out for this study also demonstrated that some research participants, with a variety of impairments, continue to face barriers when voting because electoral-assistive devices are not provided to them. This is an important consideration when implementing further measures to achieve the full realisation of the right to vote of persons with disabilities in compliance with Article 29(a) CRPD, and particularly in the context of the Elections Bill 2021.

#### ***Compliance with Article 29(a) CRPD by Spain***

The compliance by Spain with Article 29(a) CRPD was primarily assessed through a comprehensive analysis of national legislation and policy. This study also explored experiences with using electoral-assistive devices of 15 voters with disabilities and 7 election officials from Spain, to ascertain how relevant national legal and policy instruments are implemented in practice.

In Spain, Organic Law 9/2007 and Royal Decree 1612/2007, which preceded the entry into force of the CRPD, regulate on the right of some persons with visual impairments to use electoral-assistive devices when voting. The existing devices correspond to haptic aids formatted in Braille: ‘the accessible voting kit’ and a tactile ballot guide. Pursuant to Articles 4-7 Royal Decree 1612/2007, the ‘accessible voting kit’ contains: instructions in Braille; a voting envelope like the one used by other voters to place their ballot paper in it; and ballot papers inside corresponding envelopes for each of the candidates. These envelopes indicate on their covers, both in print and in Braille, the name of each candidate. Under Article 5 Royal Decree 1612/2007, voters can also use a tactile ballot guide in Braille to vote in elections to the Senate. Users of these devices must know Braille and be acknowledged as having a visual impairment in a degree equal to or higher than 33 percent or are affiliated with the Spanish National Organisation for the Blind (ONCE) under Article 3 of Royal Decree 1612/2007.

This study has noted that making available the electoral-assistive devices mentioned above is a concrete measure adopted by Spain to achieve *de facto* equality for some persons with visual impairments who fulfil the requirements established in the law. Most research participants who had used these devices reported positive voting experiences. They talked about how using the devices has enabled them to vote secretly and independently. This is an important finding, and confirms that electoral-assistive devices are an effective means of support to ensure the enjoyment of the right to vote by persons with disabilities on an equal basis with others, as required by Article 29(a)(i) CRPD. Furthermore, this study has revealed that certain socio-cultural factors have influenced the positive meaning ascribed to the existing devices by some research participants. For example, some participants talked about how the ‘accessible voting kit’ reflects social values that are important for Spaniards blind persons, and namely recognising blind persons as independent individuals and active members in society. Other participants also regarded positively the fact that the accessible voting kit and the tactile ballot guide were developed by a Spanish organisation (ONCE), which works in favour of the social inclusion of persons with visual impairments. This is an important consideration when making available new accessible voting materials, including electoral-assistive devices, given that under Articles 4(3) and 29(a)(i) CRPD, Spain is required to closely consult with persons with disabilities and their representative organisations on all aspects of the development and implementation of such materials.

The research carried for this study has also demonstrated that certain attitudes and practices of election officials proved the complexity of power relations within the voting context. For example, one election official who was interviewed for this study considered that requests of voters to using personal assistive devices, such as a screen reader on a mobile phone, must be always deny for minimising security risks and avoiding electoral fraud. As noted, such a practice is a breach of the legal duty to provide reasonable accommodations in an individual case under Article 2 of Royal Decree 1/2013 and Article 5(3) CRPD read in conjunction with Article 29(a)(i) CRPD. Other election officials also elaborated upon their lack of training on how to use the existing electoral-assistive devices, and on disability rights in general. This finding is underlined by the fact that Spain has not developed a training program on the duties of election officials to make reasonable accommodations for voters with disabilities. As noted, full compliance by Spain with Article 29(a)(i) and related CRPD provisions requires to adopt further active measures to tackle discrimination against voters with disabilities and increase

equality of opportunities for them in the context of voting. These measures must include training on disability rights of election officials.

Finally, many research participants with disabilities reported that inaccessible voting materials is a barrier for them to vote on an equal basis with others. These participants included persons with visual impairments who did not fulfil the legal requirements provided by Article 3 of Royal Decree 1612/2007 to use the existing electoral-assistive devices. This study has concluded that one pressing priority area of action that should be thoroughly addressed in the new post-2020 Spanish Strategy on Disability is participation of persons with disabilities as voters, with an emphasis on accessibility of the voting environment. The post-2020 Strategy must be informed and supported on meaningful consultation with persons with disabilities living in both rural and urban areas of the country through their representative organisations [Article 4(3) CRPD].

### **Concluding remark**

The study ‘Voting Matters’ concluded that addressing the legal and policy lacunae, as well as the *practices* within national electoral systems, identified in this study, would have a substantive impact on the effective implementation of Article 29(a) CRPD in England and Spain. Therefore, this study contributes to achieve a greater understanding of how Article 29(a) CRPD has been implemented in practice in England and Spain.

## 10 Campaigning for agenda setting vs decision-making

**Claudia Harris Coveney**

### Introduction

The two bodies of academic literature that seek to understand complex policy processes (termed governance literature here) and campaign activity undertaken by social movements (social movement literature) are disparate and do not interact sufficiently with one another. This is despite the increasing participatory role of social movement organisations (SMO) within many governance settings. The purpose of this paper is to illustrate the important distinction between ‘agenda setting’ and ‘decision making’ from the perspective of social movement campaigns in the European Union (EU). It does so by connecting governance literature and an analytical policy process model with empirical findings from a 3-year research project conducted with an EU-level civil society organisation representing the interests of the disabled people movement. The paper begins with a contextual introduction to the concept of governance and the ‘opening up’ of the EU policy system for SMOs via civil society. It then introduces the ‘Multiple Streams Framework’ approach (MSF) and notes its different applications to ‘agenda setting’ and ‘decision making’ before demonstrating this important distinction with empirical findings from a three-year research project. It is the aim of the paper to establish the different approaches and challenges SMOs face in their campaigns based on this distinction. In doing so it highlights the importance of connecting social movement literature to governance literature - for both fields.

### Governance and the EU

Jessop (2005: 111) describes the ‘discovery’ of governance ... ‘the complex art of steering multiple agencies, institutions, and systems that are both operationally autonomous from one another and structurally coupled through various forms of reciprocal interdependence’. The past twenty years has seen a ‘horizontalisation’ of these chains, a move to networks based on interactions between policy actors, rather than vertical chains of command, and an expansion of these networks to include non-government actors, citizen groups and other stakeholder representatives (Peters and Pierre, 2000: 18; Rhodes, 2012: 33; Klijn and Koppenjan, 2015). In this shift from government to governance, public officials no longer possess the requisite authority and resources to create policy on their own (Benz and Papadopoulos, 2006: 512). Other actors close to policy issues are considered legitimate experts. Multi-level governance (MLG) describes the division of decision-making across several ‘politico-administrative’ institutions and is an important dimension of European governance specifically (Marks, 1993). In MLG horizontal chains of activity are also emphasised: ‘no level of activity being superior to the other ... therein, a mutual dependency through the intertwining of policy-making activities’ (Stephenson, 2013: 817).

The sphere of European governance is characterised by decision-making across a range of political jurisdictions using horizontal networks of actors. Over the course of multiple Treaty revisions, the scope or ‘competence’ of European governance has increased. Member States within the EU have submitted significant control over their sovereignty to join the Union.

Article 15 of the Treaty on the Functioning of the European Union (TFEU) recognises civil society's role in the EU's good governance and Article 11 of the Treaty on European Union (TEU) emphasises the need for the EU to have “an open, transparent and regular dialogue”

with civil society organisations, for example when preparing proposals for EU laws. Separate from traditional party politics, the political dimension of civil society activity between State actors and non-governmental, non-profit actors is one where ideas can be introduced by organisations representing the interests of specific societal groups to influence policy debates, discourse and direction (Fraser, 1990; Habermas, 2015). The inclusion of civil society in European decision-making has historically been in the interest of the EU institutions. Its increasing presence in policy can be tracked, as Kohler-Koch (2012) describes, via the changing terminology used in Commission documents about its relationship with these organisations – from ‘involving civil society’ to ‘co-production of policy’ (see also Greenwood, 2007; Garcia & Greenwood, 2014). Part of this involves creating Commission-funded spaces for non-government groups to interact formally and informally with the European institutions. This progression has been described as the ‘Europeanisation’ of a movement (Patternote, 2015). ‘Transactional activism’ defines the ‘development of lateral ties among civil society groups and vertical ties between these groups and public officials’ (Petrova & Tarrow, 2007: 79 Rose 2001, Crotty 2003). It is a useful term for European civil society activity and the specific forms of lobbying that suit formal EU civil society arenas. European advocacy organisations are geared towards these insider, largely non-contentious strategies. Transactional lobbying refers to “relational forms of collective action in interorganisational networks – or the ties (temporary and enduring) among organised non-State actors, and between them and political parties, power holders and other institutions” (Petrova and Tarrow, 2007: p.79). Despite these terms acknowledging the presence of SMOs in governance settings, attention to the role of social movement campaigning in policy processes remains lacking. The next section will introduce the MSF approach to policy analysis.

### **The Multiple Streams Framework**

Agenda setting describes how potential issues come to be formally identified by policy makers (Kingdon 2011: 2). Kingdon’s original model contends that policy makers have a ‘multitude of problems that are thrust upon them by factors beyond their control’ (Kingdon 1995: 75). The model has since been expanded to include the longer policy process and customised for the EU context (Zahariadis, 1998; Herweg, 2016). MSF approaches examine which issues are given attention; how, why and when actors are mobilised to participate; how issues are framed and meaning is generated and how the process can be manipulated. In doing so, the ambiguity and complexity of the policy process is emphasised. The ‘problem’ stream describes the perceptions, attitudes and opinions of relevant actors about the issue, and to what extent and how well the State has managed it in the past; and the ‘political’ stream provides context to the situation: legislative deadlines, dominant ideas and values comprising national (and supra-national) ‘moods’ and the power shifts following elections, cabinet shuffles and Treaty revisions. These streams ‘open’ at a critical point to create the conditions for an idea to be offered as a policy solution (Cairney and Jones, 2016: 39). Such critical moments are ‘windows of opportunity’ to be seized on by policy entrepreneurs to secure an idea aligning with their interests to become incorporated into an accepted policy solution. (Kingdon 1984: 123). The ‘policy’ stream, setting out the types of solutions that are being put forward by relevant actors to solve the diagnosed problem, contains a finite, complex collection of ideas and possibilities.

Contextual factors might explain a change in the structure of opportunity in which a group can insert their agenda and shift focus to a policy issue – ideally with a ready-made policy solution (Agustín, 2008). Frames, defined by Snow et al (1986; 2014) as the way social actors interpret

reality, diagnose problems, suggest solutions and how to realise solutions, are a lens through which both policy and campaigns can be understood. New windows appear alongside existing institutions, parties, and public opinion that still influence their introduction and use (Kingdon, 1984). Linking policy agendas to popular discourse is captured by the concept of ‘policy framing’, where ‘policy actors try to control the prevailing image of the policy problem through the use of rhetoric, symbols and policy analysis’ (Baumgartner and Jones, in Mazey, 2000: 339). Institutions are not neutral, actor preferences are not well defined, and participation is fluid. As a result, the process is open to political manipulation in favour of those who generate information, control access to policy venues, and synchronize or exploit group, national, and institutional timetables.

The MSF has been usefully applied to the EU policy context, an environment that is highly complex and ambiguous. Political conflict is endemic and issues are frequently settled by activating certain frames as EU actors move in and out of the process. Herweg (2016) tailors the framework to suit the agenda-setting context of the EU by identifying functional elements of the framework in EU processes and which political and problem streams open policy windows. The power sharing arrangement in the EU between the Council of Ministers (the Council), the European Commission (the Commission), the European Council and the European Parliament (EP) differs greatly from the original context of Kingdon’s (1984) model of the US federal government. The following section describes the MSF in the context of the EU policy process.

Specific to the EU context is the need for policy entrepreneurs to frame the issue as a problem requiring Community-level action. The EU rule of subsidiarity calls for policy and decisions to be made at the most local level of governance possible: Member States are to be deferred to at all appropriate times. The political stream in the EU context is complicated by mixed empirical knowledge on the influence of interest groups on the European institutions (Dür, 2008; Klüver, 2013; Herweg 2016). Determining when the streams are ‘ripe’ for entrepreneurs to manipulate also needs adjustment to the EU context; in Kingdon’s (1984) original model, the political stream was ready when an issue received government support. The power-sharing institutions of the EU have varying agendas and operate with relative independence of one another. Support from the Commission in the form of a proposal, Green Paper or White Paper does not signal support at Parliamentary or Council levels. Windows of opportunity for policy proposals can open in the problem stream or the political stream. In the case of agenda setting, a window can open in the political stream through new Commission work programmes, Treaty revisions, Council and EP requests for information gathering or studies on issues by the Commission, and the EP using its indirect agenda-setting powers (Herweg, 2016: 21). The MSF has been tailored to suit the specific fragmented governance context of the EU and has been adjusted to cover specific parts of the policy process. This distinction between agenda setting and decision-making holds use for social movement literature looking at campaign activity. After defining social movement campaigns and the use of the MSF in their analysis, the paper will explore this distinction empirically.

Social movement campaigns can be defined as “temporally bounded and strategically linked series of events and interactions directed at common goals” (Staggenborg & Lecomte, 2009: 164; della Porta & Rucht, 2002: 3; Keck and Sikkink 1998: 6; Marwell and Oliver 1984: 12). Campaigns concentrate movement energies on specific goals, providing success or measurable failure, which in turn impacts movement networks and subsequent campaigns. Staggenborg &

Lecomte (2009: 177) find that “[p]revious campaigns and structural characteristics of movement communities, as well as strategies and tactics, affect the ability to mobilise new collective campaigns.” Tilly (2008) argues that campaigns impact subsequent social movement action by altering political opportunities, available models of contentious action repertoires, and connections between activists.

The MSF provides a useful lens through which to examine the campaign activity of a social movement aimed at policy change. Campaigns act as policy entrepreneurs, particularly those engaged in transactional lobbying and activism. The remainder of this paper will demonstrate the importance difference between *types* of campaign according to the distinctions made in the MSF approach. A campaign calling for the recognition of an issue by the State can be distinguished from a campaign calling for a specific policy solution once the issue has been formally recognised. The paper will show this by examining a campaign calling for an EU-level non-discrimination Directive for disabled people and a campaign that followed an internal market Directive called the Accessibility Act through the legislative process. Before this, the research project and its method are explained.

### **Research project aims and approach**

Empirical findings from a three-year research project on the campaign activity of an EU-level civil society organisation underline the important distinction between campaigning for new issues to be introduced to EU agendas and following an issue through the legislative process. The European Disability Forum (EDF) is an EU level, ‘umbrella style’ advocacy organisation representing the interests of disabled people in Europe. As an organisation it consists of around 100 member organisations. It has two types of ‘full member’ disabled people’s organisations (DPOs) with governing abilities: a national council where Member States are each represented by one DPO, and organisations of disabled people that span across Europe representing specific impairments and issues. The day-to-day activities of the organisation are carried out by a Brussels-based secretariat. This organisational structure is typical of those operating at the EU level (Marks & McAdams, 1996). Among its activities, the EDF runs targeted campaigns at specific areas of EU policy. The research project selected three campaigns as case studies for analysis: their tactics and strategies were identified and their outcomes link. Data were collected via 21 interviews with individuals connected to the campaigns; personal and organisational archival material and EU policy material. Data were processed and coded to identify problem representation: how the campaign framed an issue and whether this framing was transferred to EU policy discourse (Bacchi, 2012). The following section will explore the different approaches and challenges faced by two of the case study campaigns according to the ‘agenda setting’ and ‘decision making’ contexts.

### **Agenda setting**

The first campaign, 1Million4Disability, utilised a novel participatory instrument to prompt a proposal from the European Commission for a disability-specific non-discrimination Directive called the European Citizens Initiative (ECI). The campaign was also the first use of the ECI: an experimental tool to enhance communication between European citizens and institutions was to be formally introduced in the upcoming Treaty of Lisbon (2009). The Commission had not responded to previous demands by the movement for a disability-specific anti-discrimination Directive which had followed the 2001 Racial Equality Directive (RED). The EDF successfully mobilised its member organisations to conduct a public-facing to generate over 1 million signatures from European citizens. The organisational network of EDF members

and their members, as well as ally organisations, used a range of tactics to collect signatures within Member States such as festivals, press conferences and national media campaigns. This required the activation of networks from the EU level right down to local organisational levels. Following the successful collection of 1.3 million signatures and according to the ECI rules the Commission responded the following year. The resultant proposal from the Commission was a ‘horizontal’ non-discrimination Directive, covering a range of groups alongside disabled people, that did not receive sufficient support from Member States to become legislation. Despite an acknowledgement of the issue by the Commission, the frame used by the campaign – that disabled people in Europe needed their own Directive – was not adopted in the proposed policy. The campaign ended following this proposal, although the EDF continues to call for the passing of the horizontal Directive alongside a coalition of EU civil society organisation. Campaigns like 1Million4Disability prompt governments to acknowledge them by generating shows of public support for the issues and aims of the campaign. The campaign used ‘outward-facing’ tactics to generate this support and utilised a governance instrument to prompt a response from the Commission. While the issue was recognised by the Commission in its proposed legislation, the campaign’s frame was not completely adopted. The story of the 1Million4Disability campaign as told by the interviewees and documentary archives also confirms Herweg’s (2016) proposed adjustments to the MSF approach to suit the EU governance context: the campaign succeeded in framing the issue as requiring Community-level attention. It was told that Council would support a disability-specific Directive, but Parliament was in favour of a horizontal Directive rather than continuing a divisive, group-by-group approach to anti-discrimination. The Commission initially signalled it would propose a disability-specific Directive and surprised the campaign when, overnight, a horizontal Directive was produced. Policy entrepreneurs face fragmented agendas and interests between the branches of the Union.

### **Decision making**

The second campaign, titled the ‘Freedom of Movement’ campaign launched a second push to secure a disability-specific Directive. The first European Disability Strategy set out a decade-long framework of action from the European Commission to meet its obligations under the United Nations Convention on Human Rights (UNCRPD). Part of the Strategy was the introduction of a European Accessibility Act (EAA) to improve the production and distribution of accessible goods and services within the Internal Market. The goal of the campaign was first to call on the Commission to propose the legislation it had committed to and subsequently to following the proposal’s course through the policy process. The campaign became deeply involved in the legislative process and inserted itself into stages of decision-making it previously did not have access to. As the proposal was considered by the EP, the EDF worked to break party lines of voting and avoid a weakened position being sent to the Council. While the EDF succeeded in negotiating late-stage amendments to the legislation at parliamentary level, and in participating in consultations at Council level, the final EAA did not cover areas like the built environment and household appliances with its requirements. Campaigns that follow issues through decision-making processes once they have been acknowledged by the State must utilise ‘insider tactics’ to track policy proposals. The Freedom of Movement campaign focused on maintaining the framing of the issue according to the interests of disabled consumers in Europe, following the legislation through the stages of the EU policy process over almost a decade. The EDF and its campaign partners attempted to defend the proposed legislation against conservative industry interests unsupportive of more regulation. While some

strategies were outward facing in the 8-year campaign, including a series of recorded videos interviewing disabled Europeans about why they needed a ‘strong’ EAA circulated on YouTube, and a protest outside the EP in March, 2017, the majority of the campaign activity targeted representatives from the European institutions, lobbying them to vote and act according to the campaign aims rather than the interests seeking a weaker proposal. Interviewees reported mixed emotions about the resultant EAA. The EDF continues to support its member organisations in the transposition of the Directive as it is moved into national legislation. This campaign seeking a specific legislative response began with the benefit of its prior recognition as an issue by the Commission. Despite this throughout the 8-year timeline it faced many challenges to the framing of the issue of inaccessibility in the Internal Market preventing disabled people from exercising their fundamental rights as EU citizens. Again, fragmented agendas specific to the governance context of the EU played a role in the campaign. The campaign is reported as a partial success by interviewees, as the transposition of the legislation continues.

### Conclusion

This paper has highlighted an important distinction between agenda setting and decision making in both theoretical and empirical terms. It has demonstrated the different challenges faced by social movements in their campaigns for policy change and pointed to the tactics employed by two case study campaign to face these challenges. The MSF approach has been utilised to demonstrate its use in social movement analysis and distinguishing between ‘agenda setting’ and ‘decision making’ contexts. Approaches to analysis and campaigns themselves should be tailored to the relevant stage of the policy process. The contextual impact of the stage of policy process being targeted by a campaign on its outcomes would benefit from further focused research. Such attention would provide a more clarified understanding of social movement campaigns and policy processes to the benefit of SMOs operating within these spheres.

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## 11 Participant perspective on similarities and differences between the movements

**Aoife Price**

### Introduction

This chapter focuses on a section of findings from research which looks at participant perspectives on similarities and differences between the movements of study, the disability and women's movement. The chapter draws from 52 qualitative one to one interviews, with participants from 23 European countries, that were conducted as part of this research. When looking at this aspect of the research there were clear similarities and differences between the two movements. They both had similar and different approaches, challenges and outcomes. The chapter will explore a number of specific areas where comparisons were drawn including fighting oppressive systems, the vastness of both groups internally, being open to new people, the socio and economic differences, influence, connection and links with government, as well as the ability to mobilise.

### Similarities and Differences

#### *Fighting oppressive systems*

People agreed that both movements were part of a minority group involved in fighting oppressive systems and creating a more equal society. Although one group holds a much larger and more dominant majority than the other. Mary (K) spoke about how both movements “focus on society as the problem, but just with different perspectives. So, you know feminism focuses on the cultural and the context that provide this patriarchal society that basically limits women from achieving their full potential. Disability is quite similar in that sense, but also, it's about barriers, the additional barriers that you face whether they're physical or attitudinal”. Liz believes that the movements have “a shared understanding of oppression and how we can dismantle oppression”. Bella proposes that there is “only one oppressive system but it's oppressive against many different minority groups”. Embla builds on this idea by explaining that the movements work to “try to escape from this masculine way of thinking about life in general” and believes “feminism as an ideology is really useful” for both the movements.

#### *Defining of groups*

The women's movement is vast and diverse as is the disability movement with different strands, political views and focuses. These groups are often contending with each other for limited resources. Diane talks about how the disability and women's movement are wide and varied and there is no one definite group that represents everyone and what you find is these groups are competing with each other for resources she said, “you see different groups vying for positions and order... often to try and have more resources rather than saying well we all deserve to have more of the cake rather than arguing over a slice of it”. Magda talks about a feminist and human rights backlash which is being driven by neoliberalism she believes “it becomes more and more difficult in my view to build strategic alliances due to conflicting interests or the lack of resources or the fact that NGOs, civil society organizations and so on. They have to compete for resources. Instead of becoming allies, we are almost like... it's almost like in the business field. You are a competitor”.

### *Openness to new people*

The issue of being open to new people joining is an important one in terms of longevity and sustainability of the movements however many were of the belief that it is not easy to join and make changes. Milesa believed that both movements were not open to new people and set in their ways when she said, “it seems that neither movement is open for new people. That is the issue especially with the disability movement; There are the same management structures over 20 to 40 years”. She goes on to say that “they're not willing to learn from new stuff, ways of management, modern directions in world disability movement”. Theresia on the other hand believed that the disability movement was more open to new people and difference when she said, “we could much better cope with difference. In making space for different ways of doing things and different bodies”. The issue of being open to new people often goes hand in hand with issues around accessibility. Zara spoke about how “the women’s movement tend to intellectualize stuff in a way that makes it very inaccessible whereas although the same can happen in the disability space, because of the self-advocacy movement and because of learning disability as a cohort of the disability space, we tend to at least have easy read and accessible formats of stuff available”. She believes that the women's movement need to make “an active choice” to make itself accessible.

### *Influence*

Most participants agreed that the women’s movement overall had a greater influence than the disability movement. This was down to their numbers, structures, and their strong history as a social movement. Gordana, and others talk about how “the women's movement is much older than the disability one. So, basically, they have much more experience on discrimination and how to fight discrimination... I feel the disability can learn and use experience from women to fight for their rights”. Women have had access to tables of power for longer than disabled people for example there are “more women in politics than there ever have been disabled people. They've been getting access into boardrooms and to corporate structures and all that...I mean it's beginning to change... disability is nowhere near that” (Mary K). Pirkko spoke about the access to politics at a European level that the European lobby has by saying “I've seen the difference because the whole gender equality agenda, they have their own structures in the Commission, they have their own structures in the parliament, they have the FEMM committee in the parliament, they have more structures and a stronger basis, legal basis and European legislative basis to work on so I feel EWL has a stronger platform to work from and is in some ways easier platform to work on” she went on to say that “it's so much more effective, its stronger, it's like twenty 30-40 years ahead of us in the disability movement”. The difference in level of access and political influence that both movements have is clear. Lessons can be learnt from the women’s movement and over time the disability movement has strengthened but it is questionable, given the sheer strength in numbers of the women’s movement, if it will ever be close in terms of overall influence.

### *Socio economic and educational disadvantage*

Some of those interviewed spoke about the challenges in obtaining mainstream education in their early years and challenges within the educational system. Bella explained that in the Turkish context disabled people have “lower levels of education and that they are often just trying to keep themselves alive whereas people involved in women’s organizations often have higher education levels and can support each other a lot more”. Access to basic education is one of the additional challenged that disabled people face when compared to non-disabled

women. Carmen went on to speak about employment opportunities and how “most of them [disabled women] don't have a job, most of them are even facing regular abuse, and on top of all of that they're supposed to make all these demands. It's very hard. I think a lot of it comes out of the social abuse that they've received over many years and the need to be recognized as valued people to defend their space”. These additional challenges that disabled people face can affect progression and in turn involvement and strength of the movement.

### ***Connection with government***

This strong connection and links with government that the disability rights movement has in some countries was raised as a distinct difference between the disability and women's movement. As Agnieszka said “in certain countries, disability rights movement is much more connected to the government. For example, in Poland this is the case... So, it is this is a completely different positionality of the movements you know?” Idil also held this belief and spoke about how “disability policies are focused on, more on economic conditions making the government as a partner for disabled organization” whereas “actually women are fighting for, against the government”. The idea of working with and for the government as opposed to against or as agents of change was something of concern to some of those who were interviewed.

### ***Ability to mobilize***

The ability to mobilize was seen as a key difference between the two movements, Bella noted that in Turkey “women are stronger because they can... I mean, in... I mean, they don't have any barriers to come together for example. So, they can meet anywhere they want and how they want and they can show themselves as a big community when they gather, for example on Women's Day or I don't know. They can just say that tomorrow they are going to meet at a time on that place and then it's done but it's not that easy or that simple for disabled people to gather and to create those spaces where they can have their voice heard or they can be visible”. Courtney spoke about the nature of disability and having to take into account “they do have disabilities, so not everything is going to get done quickly, and things will take time”. Gordana also reflected on this by saying “if you are a woman you can fight for your rights, going to meetings. There will be local government organisations etc. There is not really barriers in that way. If you are a woman with a disability, then you are faced with a number of barriers. First of all with the architecture... Then there is a question of personal assistance.. I could not go to any meeting without my personal assistant... so I think that for advocates and disability, it is much more to fight for our rights than women”. The complexity of organizing and issues around accessibility is one that is unique to the disability movement. It affects ability to participate and mobilise and adds an additional layer of expense on the movement.

### ***Issue areas***

The issues that both movements have to deal with is something else that distinguishes them from one another. The disability movement continue to have to work on the most basic of human rights whereas the women's movement have been able to progress and tackle more complex issues. The “disability rights movement really deals with a lot of basic needs, with economic exclusion, and maybe this is why sometimes is super resistant to tackle issues that are more of, I don't know, like cultural basis” (Agnieszka). Diane talks about the disability and womens movement being in very different places she says that she thinks the number one issue for the women's movement is a trans question and for the disability movement it is about accessibility “because if you can't leave your home and you can't get on public transport or you

can't go somewhere, that's it; you can't go to school, you can't go to work you can't go to see your friends or get involved in your community". She doesn't believe there is "one thing that brings the two movements together". Katrin speaks about the basic issues that the disability movement are trying to address and how we "still have member states where persons with disabilities are not allowed to vote". Pirkko also speaks this point and talks about when she worked with "the women's movement it felt different because it was one issue, one perspective only, it was completely focused on that and it was easier to work with rather than the myraid of issues that the disability movement because of the heterogeneity has to deal with, so it was more homogeneous" she went on to say "we have such a diversity within our movement and that the needs and the situations of people are very different dependent on what their particular impairment is or what the situation in the country is for example the voting issue, for the women's movement when I told them about the campaign of the disability movement to have voting rights in the European elections, they were like, 'what are you talking about?' I was referring to Inclusion Europe and the campaign to allow voting so from the disability movement we have a lot of variety of issues to bring forward".

### *Solution focused*

People spoke about the proactive nature of the women's movement in comparison to the disability movement. It should be noted that this could be due to resources and other issues noted above. Courtney was of the belief that the feminist movement was more solution focused than the disability movement and said, "feminist movement see if there is a negative, they then do a campaign or trying to do something about it, but say for disabilities, is kind of can just be left to just complaining and there's not actually being any real action done". Mary K talks about the disability movement needing to be more solution focus when she asks "how do we turn the adversarial approach into a problem-solving approach question and into a solution giving perspective, rather than always saying 'we're left behind. we're forgotten. Where the last billion people that haven't been thought of.'" she goes on to say "our differences are about, if I was honest, about actually strategizing real change. I think that the women movement have done that pretty successfully for women's issues" Pirkko talks about how the European Women's Lobby spend a lot of time working towards consensus and sometimes it can take a long time to even get basic things done but did say that this had benefit in the end when everyone agreed, "they use a huge amount of time, energy, meetings, money and brainpower to develop terms of reference, develop processes... I'm a little concerned that it takes forever to develop terms of reference and that we use an inordinate amount of time to look at something like minutes and formal things but that's also one type of safeguards to ensure that when decisions are taken they are collectively approved". However Rhoda when referring to the situation in Malta talks about how she believes in that country the disability movement has been more effective in terms of solutions and legislative change, in saying "I think that disability sector has properly been slightly more effective in getting things like legislation passed and things like that".

### **Conclusion**

It is clear from the findings that there are similarities and differences when it comes to the issues explored in this chapter. Both groups are seeking to fight oppressive systems and are part of a minority group, considering one group is a much larger minority than another. The women's movement has more members, history and influence and were seen as a dominant group with access to many spaces that the disability movement did not yet have access to. Within both movements there are different branches or stands with different visions and focus.

There are limited resources that end up being divided within both movements because of the diversity and therefore some people were of the belief that this weakens them in terms of collective action. It is important to be open to new people and members for a movement to grow and have longevity but many of those interviewed felt that both movements were closed off and set in their ways. The economic and educational differences among members of both movements was raised along with the ability to mobilise. Disabled people can not easily mobile in the same way as the women's movement, because of issues of accessibility it is often very difficult to meet at short notice or take part in traditional demonstrations that other social movements would tend to have. The relationship and link with government was explored and the idea of the disability movement being more compliant with government compared to the women's movement was seen as a distinct difference in some countries. When it came to issue areas the disability movement had to deal with a lot of basic issues and diversity of issues within their movement whereas the womens movement was seen as dealing with more of a singular issue and were quite advances in the issues they were campaigning for. Some felt that the womens movement was more solution focused than the disability movement and that the disability movement spent time pondering on their difficulties rather than working towards progressive change. However having said that in some countries such as Malta there was a perception that the disability movement has been more effective in terms of influencing legislative changes. It is clear from this research that there are similarities and differences between the movements. Both movements would do well to reflect on these and learn from each other's experiences.

## 12 Operationalising the principle of nothing about us without us in National Human Rights Institutions

**Colin Caughey**

National Human Rights Institutions (“NHRIs”) played a key role in the development of the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”). One of the most unique features of the CRPD is the requirement on states to designate an Independent Monitoring Mechanism (IMM). This requirement is set out at Article 33(2) of the CRPD:

“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.”

In requiring the development of domestic architecture to promote compliance the drafters of the CRPD sought to build on the pre-existing network of NHRIs.<sup>1</sup> Article 33(2) makes reference to NHRIs, and in practice NHRIs have been designated as their state’s Independent Monitoring Mechanism (IMMs).<sup>2</sup> As the literature concerning Article 33 demonstrates, there was significant hope that NHRIs designated as IMMs would collaborate effectively with disabled people and their representative groups in order to influence domestic politics.<sup>3</sup> In this article I will provide a brief overview of my empirical research which has reviewed how NHRIs are collaborating with DPOs to strengthen the voice of the disabled people’s movement. I will discuss my key finding that NHRIs that have been designated as IMMs have not yet fully considered how the principle of ‘nothing about us without us’ can be fully reflected in monitoring the implementation of the CRPD. This finding has been informed by empirical research which has reviewed existing approaches by NHRIs.

My principal method of research was a case study analysis of the situation in Ireland and in the UK. I recognised that I needed to comprehensively review the relationship between NHRIs and DPOs in real world scenarios. Yin recommends that explanatory case studies be utilized where

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<sup>1</sup> Meredith Raley, ‘The Drafting of Articles 33 of the Convention on the Rights of Persons with Disabilities: The Creation of a Novel Mechanism’ (2016) 20 *IJHR* 138

<sup>2</sup> Janet E Lord and Michael Ashley Stein, ‘The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities’ (2008) 83 *Wash L Rev* 462

<sup>3</sup> Quinn, ‘Resisting the “Temptation of Elegance”’: Can the Convention on the Rights of Persons with Disabilities Socialize States to Right Behaviour?’ in Oddny M Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Person with Disabilities: European and Scandinavian Perspectives* (Martinus Nijhoff 2009), p. 252

a researcher is seeking to explore a relationship.<sup>4</sup> Yin defines a case study as " ... an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident".<sup>5</sup> I therefore selected an explanatory case study as my principal method of enquiry

### Pluralist character of NHRIs

The Paris Principles, which set out the essential features of a NHRI, require that NHRIs are pluralistic. The composition of a NHRI should reflect the composition of society.<sup>6</sup> The Office of the High Commissioner for Human Rights has confirmed, 'pluralism is best demonstrated when an institution's membership visibly reflects the social forces at play in the State'.<sup>7</sup> The Paris Principles do not prescribe a specific approach to ensuring pluralism. Pluralism is a malleable concept which can depend upon local contexts and traditions.<sup>8</sup> The Global Alliance of NHRIs, the professional body for NHRIs, has elaborated on how pluralism can be reflected within a NHRI including through diverse membership of a decision-making body; through inclusion of societal groups in the appointments process; through procedures enabling effective cooperation with diverse societal groups (for example advisory committees); and through the staff.<sup>9</sup>

The participation of civil society within a NHRI is considered an essential safeguard to ensure the independence of the NHRI. The involvement of civil society is seen as a counterbalance to the role of the state in establishing and funding an NHRI.<sup>10</sup>

Much of the literature relating to the designation of NHRIs as IMMs has presumed that as pluralistic bodies NHRIs will have developed participative ways of working with civil society. It was hoped that these ways of working would provide a foundation for the development of bespoke arrangements to facilitate the participation of disabled people and DPOs in the monitoring of the UNCRPD.<sup>11</sup> However, in my evidence gathering I found that there has been a lack of exploration of the relationship between NHRIs and civil society. NHRIs do not necessarily have effective mechanisms for engaging with civil society.

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<sup>4</sup> Yin, R. K. *Case study research: Design and methods*. Beverly Hills, CA: Sage. (1994).

<sup>5</sup> *Ibid* p. 23

<sup>6</sup> UN General Assembly 1993. *Principles relating to the status and functioning of national institutions for the protection and promotion of human rights ('Paris Principles')*. Resolution 48/134, UN Doc. A/RES/48/134.

<sup>7</sup> OHCHR (n. 303)

<sup>8</sup> Meuwissen, K *NHRIs and the State: New and Independent Actors in the Multi-layered Human Rights System?* *Human Rights Law Review*, Volume 15, Issue 3, September 2015, Pages 441–484 pg 454

<sup>9</sup> SCA (n. 306) para 1.7

<sup>10</sup> Gonzalo Elizondo and Irene Aguilar, "The Ombudsman Institution in Latin America : Minimum Standards for its Existence", *National Human Rights Institutions, Articles and working papers*, Edited by Birgit Lindsnaes, Lone Lindholt, Kristine Yigen, The Danish Centre for Human Rights, s. 209-222. pg 217

<sup>11</sup> Meredith Raley (2016) *The drafting of Article 33 of the Convention on the Rights of Persons with Disabilities: the creation of a novel mechanism*, *The International Journal of Human Rights*, 20:1, 138-152 p. 140

Pre-existing literature focuses on how the requirement that a NHRI be pluralistic can provide a bulwark against the independence of the NHRI being encroached upon by the state. The pluralistic character of a NHRI has rarely been examined as a feature which supports both its effectiveness and the effectiveness of civil society. The Paris principles do not offer guidance to how individuals who have been appointed as members of a NHRI should manage their relationship with sectors of society or with any CSO.<sup>12</sup> There is also a slight conflict between the emphasis which the CRPD

As set out, the GANHRI Sub Committee on Accreditation has made clear that office holders should act in their individual capacity. NHRI representatives broadly support this position.<sup>13</sup> However this position stands in stark contrast to the emphasis which the CRPD and CRPD Committee place on disabled people being represented through their representative groups.<sup>14</sup>

NHRIs are responding to emerging jurisprudence from the CRPD Committee by establishing advisory committees. A model which was reflected in both of my case studies during my evidence gathering. Notably in both NHRIs individuals have been appointed to advisory committees in their individual capacity rather than as representatives of their organisation. I observed that the appointment of members on an individual basis undermines the potential for these advisory committees to support the development of the DPM and the potential for advisory committees to act as a mechanism for engagement with DPOs.

Whilst individuals may be appointed to a NHRI's decision making body due to their membership or knowledge of a specific group when appointed it is expected that they will have regard for the rights of all individuals when taking collective decisions. The GANHRI provides that office holders must be appointed 'to serve in their own individual capacity rather than on behalf of an organization they represent'.<sup>15</sup> Whilst the GANHRI suggests that representatives of sectoral interests within an advisory committee is acceptable, their inclusion in decision making bodies is not. NHRI representatives interviewed for this research shared the view of commentators that if NHRI office holders were appointed to represent sectoral interests this may lead to office holders placing the priorities of certain sectoral groups over the priorities of the NHRI.<sup>16</sup> Furthermore there is a concern that it may undermine collegiality amongst members and create division.<sup>17</sup>

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<sup>12</sup> De Beco G and Murray R, A commentary on the Paris principles on national human rights institutions (Cambridge University Press 2014) p. 67

<sup>13</sup> Quinn, Gerard and Crowther, Neil 'Human rights and disability: A Manual for NHRIs' (Asia Pacific Forum 2017), p. 111

<sup>14</sup> UNCRPD Article 4(3)

<sup>15</sup> GANHRI General Observations of the Sub-Committee on Accreditation 2018, para 1.8

<sup>16</sup> Murray, R and Johnson K, 'Implementation of Article 33 CRPD in the United Kingdom: The Need to Consolidate Civil Society Engagement' in Gaulthier De Beco (ed) *Article 33 of the UN Convention on the Rights of Persons with Disabilities National Structures for the Implementation and Monitoring of the Convention* (Brill 2013) p. 98

<sup>17</sup> Anne Smith, 'The Unique Position of National Human Rights Institutions: A Mixed Blessing?' [2006] *Human Rights Quarterly* 937

Disabled people and their representative organisations have often been absent from domestic discussions relating to the establishment of NHRIs. However, in recent years DPOs have taken greater interest in the establishment and effectiveness of their NHRIs. For instance, the Belgian Disability Forum has called on the Belgium Government to ensure the establishment of a NHRI.<sup>18</sup> A number of DPOs have provided comments on the performance of NHRIs designated as IMMs during the CRPD Committee's periodic examinations of states compliance.<sup>19</sup>

There is surprisingly limited literature assessing the benefits which the establishment of a NHRI can bring to civil society. Some commentators have highlighted the role of a NHRI in providing a bridge between civil society and the state. Anne Smith has suggested that NHRIs can provide civil society with 'channels to make their claims' to the state.<sup>20</sup> The conceptualisation of NHRIs as the bridge between civil society and the state is premised on the assumption that channels do not already exist. Literature relating to the DPM tends to emphasise that participative structures do exist, but these are ineffective.<sup>21</sup> Indeed the establishment of the CRPD has led many states to develop new participative structures. The establishment of the CRPD has also encouraged many NHRIs to review their participative structures and to consider how they can include disabled people and their representative groups in monitoring the CRPD.

NHRIs in both of my case studies had chosen to include disabled people and their representative groups in their monitoring activities through establishing disability advisory committees. My case studies therefore provided unique insights into the effectiveness of this arrangement.

I discovered that through their activities NHRIs can provide informal policy-oriented learning opportunities to DPOs.<sup>22</sup> Most significantly, I found that individuals included in the disability advisory committees (DAC) of both the Equality and Human Rights Commission (EHRC), in the UK, and the Irish Human Rights and Equality Commission (IHREC) were presented with opportunities for policy-oriented learning. Members of the IHREC DAC, in particular, noted that through participation in the DAC they had gained insights into the policy making process and significantly strengthened their capacity to engage in human rights discourse.<sup>23</sup> This could

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<sup>18</sup> Belgium Disability Forum, 'Submission to the XXI session of the CRPD Committee List of issues prior to reporting for Belgium' February 2019

<sup>19</sup> Ibid

<sup>20</sup> Anne Smith, 'The Unique Position of National Human Rights Institutions: A Mixed Blessing?' [2006] *Human Rights Quarterly* 937 p. 909

<sup>21</sup> Lana Moriarty and Kevin Dew, 'The United Nations Convention on the Rights of PWDs and Participation in Aotearoa New Zealand' [2011] *Disability & Society* 685 p. 686

<sup>22</sup> True, Jacqui, and Michael Mintrom, 'Transnational networks and policy diffusion: The case of gender mainstreaming.' [2001] *International Studies Quarterly* 27

<sup>23</sup> Colin Caughey, *Amplifying Disabled People's Voices: The Role of National Human Rights Institutions* (Unpublished Thesis), Chapter 6 (6.6.4)

indirectly benefit Disabled People's Organisations as a number of members of the DAC also hold senior positions within such organisations. However, this is not the case for all members and there is no guarantee that individuals appointed to either institution's DAC who are staff members in DPOs will share their expertise with their employers or organisations.

The experience of the EHRC and IHREC DACs suggest that through developing participative structures a NHRI can develop policy-oriented learning networks.<sup>24</sup> The fact that members of the DACs of both the EHRC and the IHREC are appointed as individuals rather than as representatives of DPOs creates a risk that the DPM will not benefit from the learning opportunities which they present. Ensuring that members of a DAC are appointed by DPOs would provide a greater degree of certainty that the skills and insights which they garner from participation in formal mechanisms will be shared with their organisations and with the broader movement.

In addition to assessing the impact of participation in the DAC on its members I also assessed how the establishment of a DAC impacted on the NHRI's overall engagement with the disabled people's movement. Whilst neither the IHREC nor the EHRC have developed formal arrangements for consulting CSOs, staff in both institutions indicated that they will often informally contact representatives of CSOs whom they consider experts on the subject of a consultation.<sup>25</sup> Human rights NGOs similarly reported that they often discuss proposed reforms with both the IHREC and the EHRC. Both institutions therefore appear to have an informal collection of CSOs whose expertise they seek when formulating their submissions on policy issues. These collections may be classed as what Peter Haas refers to as an 'epistemic community', composed of organisations considered to have valuable evidence and views which a NHRI can draw on when developing their submissions.<sup>26</sup> Neither the EHRC nor the IHREC staff indicated that DPOs were included within their informal epistemic communities. This suggests that the expertise of DPOs is not sufficiently valued by either NHRI.

The failure to include DPOs within informal networks appears in part to be a consequence of each institution having established a DAC. I would posit that the establishment of a DAC composed of individuals provides a valuable resource to NHRI(IMM)s but dissuades NHRI(IMM)s from developing relationships with DPOs to coordinate engagement in the policy making process. Whilst disabled people on the DAC may make important contributions in the formation of the NHRI(IMM)s advice, the DPM will lose out on the opportunity to develop more constructive and longer lasting relationships with the NHRI(IMM). A potential consequence of the establishment of a DAC may therefore be that a NHRI de-prioritises engagement with DPOs as it has its own in-house source of expertise. Such a consequence undermines engagement with the broader movement and is not in my view in the spirit of the UNCRPD which specifically acknowledges the importance of engaging with disabled people through their 'representative groups'. There is a need for reflection within NHRI(IMM)s on

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<sup>24</sup> Diane Stone *Learning Lessons, Policy Transfer and the International Diffusion of Policy Ideas* (University of Warwick 2001)

<sup>25</sup> Colin Caughey, *Amplifying Disabled People's Voices: The Role of National Human Rights Institutions* (Unpublished Thesis), Chapter 6 (6.7.4)

<sup>26</sup> Peter Haas, *Introduction: epistemic communities and international policy coordination* (Cambridge University Press, 2009)

the potential benefits which the inclusion of representatives of DPOs on advisory committees can contribute.

My overarching conclusion is that there is a need for further reflection on what it means to operationalise the principle of ‘nothing about us without us’ amongst those NHRIs which have been designated as IMMs. NHRIs have a concern that to include DPOs in all their monitoring activities may create governance issues and may dilute the unique status of a NHRI as a trusted adviser of government. This concern is not completely unfounded. NHRI representatives highlighted that their staff and officers have often developed constructive working relationships with civil servants who tend to grant them greater access due to their status as public servants. These relations could potentially be undermined if NHRI staff sought to include DPOs.<sup>27</sup> However there are many circumstances in which the inclusion of a DPO could potentially enrich discussions. There is a need for reflection on when it is appropriate for a NHRI to realise the principle of ‘nothing about us without us’ through including a DPO representative in a meeting and when it is possible to realise the principle through other measures. Overall, NHRIs need to develop their confidence in engaging in participative working practices.

The relationship between NHRIs and DPOs in both of my case studies would benefit from an open discussion on where it is and is not possible to include disabled people and their representative groups. An open discussion on the ways in which a NHRI can influence change is also necessary. DPOs in both of my case studies tended to have a high expectation that a NHRI can effect change through the exercise of their powers. NHRI representatives interviewed for this research tended to be more circumspect and less confident of their ability to effect change. It is important that NHRIs engage in open and honest conversations with DPOs about the level of influence they exert.

NHRIs also need to reflect on how they make and explain their decisions. As institutions with broad mandates NHRIs inevitably must make strategic decisions on issues which are prioritised and those that are not. If a NHRI does not seek to explain its decision-making process to DPOs, there is potential for a perception to develop that a NHRI is unresponsive to civil society requests. This can lead to a breakdown of trust in the institution which can have long-term damaging effect.

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<sup>27</sup> Pegram, Tom ‘The New Architecture in Global Human Rights Governance’ *Millennium* vol 43(2), p 618-639, 2015

## 13 The Participation of European Organisations of Persons with Disabilities in the State Reporting: Why does the Convention on the Rights of Persons with Disabilities matter?

**Hanxu Liu**

### Abstract

Organisations of persons with disabilities, particularly those from European countries, have a long history of interacting with UN human rights bodies and have contributed significantly to the negotiations of the UN Convention on the Rights of Persons with Disabilities (CRPD). After its ratification among the EU Member States, existing studies rarely focused on OPDs contribution to the CRPD's monitoring mandate, although public documents show plentiful output from local and national OPDs to relevant activities. This article provides a legal interpretation on a core participation provision – Article 4(3) in the Convention, and investigates the relevance of its application with ensuring OPDs' participation in the CRPD State Reporting procedure of 24 examined European countries according to empirical evidence. Discussion in this article shows that OPDs' participation in this UN procedure reflects some key issues in the State's full compliance with its CRPD obligation to promote the 'full and effective' participation of persons with disabilities in decision-making processes.

### Introduction

The Convention on the Rights of Persons with Disabilities, coupled with its Optional Protocol (OP-CRPD), appoints the Committee on the Rights of Persons with Disabilities (CRPD Committee) as its main monitoring body.<sup>1</sup> State Reporting is a crucial task under the CRPD Committee's monitoring function under the CRPD Article 36, which refers to a mandatory procedure that requires States Parties to submit reports on the implementation of treaty obligations for the Committee's considerations.<sup>2</sup> With a wide and longstanding utilisation by UN human rights treaty bodies, a State Reporting process typically contains three stages: the

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<sup>1</sup> UN General Assembly, 'Convention on the Rights of Persons with Disabilities' (2007) A/RES/61/106 Article 33 to 39. UNGA, Optional Protocol to the Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered into force May 3 2008) A/RES/61/106, Annex II.

<sup>2</sup> Ornella Ferrajolo, 'Article 34 [Committee on the Rights of Persons with Disabilities] Article 35 [Reports by States Parties] Article 36 [Consideration of Reports]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017).

adoption of List of Issues,<sup>3</sup> the State review session,<sup>4</sup> and the adoption of Concluding Observations.<sup>5</sup>

Like its counterparts, the CRPD Committee acknowledges and welcomes civil society actors' participation in the State Reporting procedure, especially Organisations of Persons with Disabilities (OPDs), in its work.<sup>6</sup> OPDs are civil society organisations composed of and led by persons with disabilities.<sup>7</sup> Local and national OPDs often utilise the recommendations in Concluding Observations raised by the CRPD Committee in national advocacy to ensure effective implementation of their human rights.<sup>8</sup> Unsurprisingly, these OPDs, including those from European countries, have considered writing alternative reports for State Reporting as one of their crucial tasks.<sup>9</sup> Alternative reports<sup>10</sup> provide information on a State's implementation of an international human rights treaty and are submitted by parties other than the State under review. Treaty bodies commonly used them as a source of additional information and validation for the consideration of State reports.

Participation is an underlined theme of the CRPD that runs through its whole text, and is reflected in its preamble and general principles.<sup>11</sup> This is a natural continuation of the active involvement of civil society, particularly OPDs, during the CRPD drafting history. Scholars consider OPDs as the main components of national and international disability movements,

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<sup>3</sup> Or the List of Issues Prior to Reporting for periodic reviews after the initial review. In List of Issues, the treaty body raised questions for State to provide clarification or further information.

<sup>4</sup> Refers to the constructive dialogue during treaty body's regular sessions.

<sup>5</sup> In Concluding Observations, the treaty body raised concerns and address recommendations for improvement in State's national implementation.

<sup>6</sup> Luigino Manca, 'Article 33 [National Implementation and Monitoring]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017); Committee on the Rights of Persons with Disabilities, 'Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the Work of the Committee' (2014) UN Doc CRPD/C/11/2.

<sup>7</sup> OPDs are also known as Disabled People's Organisations (DPOs). This paper adopts the term and definition of OPDs in Committee on the Rights of Persons with Disabilities, for details, see Committee on the Rights of Persons with Disabilities, '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' (2018) UN Doc CRPD/C/GC/7 paras 11–12.

<sup>8</sup> IDA, 'Guidance Document: Effective Use of International Human Rights Monitoring Mechanisms to Protect the Rights of Persons with Disabilities' (2010).

<sup>9</sup> Anne Waldschmidt and others, 'Implementing the UN CRPD in European Countries: A Comparative Study on the Involvement of Organisations Representing Persons' in Rune Halvorsen and others (eds), *The Changing Disability Policy System: Active Citizenship and Disability in Europe* (Routledge 2017).

<sup>10</sup> Also known as shadow reports.

<sup>11</sup> UN General Assembly (n 1) preamble(o) and article 3 (c); Michael Ashley Stein and Janet E Lord, 'Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, Lost Opportunities, and Future Potential' (2010) 32 *Human Rights Quarterly* 689, 697.

and the latter heavily facilitated and influenced the CRPD's negotiations, as numerous studies indicated.<sup>12</sup>

Against this backdrop, this article aims to provide an interpretation of the legal basis and the State's obligations related to OPDs' participation in the CRPD State Reporting procedure and presents some preliminary findings regarding the situation and issues of OPDs participation. These findings emerged from the author's ongoing PhD study, which investigated the participation of local and national OPDs from 24 examined European States (European OPDs).<sup>13</sup>

This paper is organised in the following way. After this introductory section, the second section provides a legal analysis of related State obligations arising from the CRPD Article 4(3), and then on the UN rules and principles that govern the engagement of civil society, including OPDs, with the CRPD Committee. The third section provides an overview of OPDs participation in the State Reporting procedure in the examined 24 European States and the issues that emerged from empirical research. Discussions and conclusions are offered at the end to reflect European OPDs experience.

This paper adopted document analysis for empirical research, and data are mainly drawn from 446 pieces of public documentation collected from the UN database.<sup>14</sup> These documents are comprised of the State's Report, List of Issues, Replies to the List of Issues, Shadow Reports and Concluding Observations for each State's reporting procedure issued by the end of 2021, as well as Alternative Reports from European OPDs and other civil society actors. Therefore, it is important to note that some of the information might be outdated or incomplete depending on when it was provided.

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<sup>12</sup> See Colin Barnes, Geof Mercer and Tom Shakespeare, *Exploring Disability: A Sociological Introduction* (Wiley 1999); Maya Sabatello and Marianne Schulze, *Human Rights and Disability Advocacy* (University of Pennsylvania Press 2013) 6; Theresia Degener and Andrew Begg, 'From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations' in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017).

<sup>13</sup> This study focuses on current and previous EU Member States. The selected 24 countries are European States Parties of the CPRD which have been reviewed at least once by the CRPD Committee by the end of 2021, including 23 EU Member States (Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden,) and a former Member State – the United Kingdom.

<sup>14</sup> UN Treaty Body Database, 'Treaty Bodies Countries' <[https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Countries.aspx](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Countries.aspx)> accessed 2 August 2022.

## Legal Analysis on the Participation of Organisations of Persons with Disabilities in the State Reporting

The CRPD Article 4(3) provides for a general obligation on States to 'closely consult with and actively involve persons with disabilities', in every step of decision-making process related to implement the Convention and on 'issues relating to persons with disabilities'. More specifically, the consultation and involvement should include 'children with disabilities', and be conducted through 'their representative organisations', in other words, OPDs. The duty to consult with civil society and OPDs followed models set in several previous international rules and instruments by International Labour Organization and the UN.<sup>15</sup>

This duty applies to the implementation of all substantive rights enshrined in the Convention and is closely linked to other provisions in the CRPD.<sup>16</sup> It first falls into the scope of a general principle in Article 3 (c) to promote the 'full and effective participation' of persons with disabilities in society.<sup>17</sup> Governments' consultations and OPDs involvement in decision-making processes comprise two of the many forms of the 'participation' in the Convention.<sup>18</sup> In practice, the positive obligation enshrined in Article 4(3) also comes hand in hand with the right of participation in political and public life in Article 29(b), which highlights the value of participation through civil society organisations, especially encouraging the formation of OPDs that represent people with disabilities at international, national, regional and local levels.<sup>19</sup> More importantly, the participation provision in Article 33(3) extends States' obligation to national monitoring, which requires OPDs to participate, and involve fully in the 'monitoring

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<sup>15</sup> These documents include: the 1975 Declaration on the Rights of Disabled Persons, the 1983 ILO Convention No. 159 concerning Vocational Rehabilitation and Employment (Disabled Persons), ILO Convention Concerning Indigenous and Tribal Peoples in Independent Countries, 1989 and the UN Standard Rules.

<sup>16</sup> Andrea Broderick, 'Article 4 General Obligations' in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018) 135.

<sup>17</sup> Valentina Della Fina, 'Article 3 [General Principles]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017) 127.

<sup>18</sup> See Riku-Heikki Virtanen, 'Towards a Permanent Consultation Mechanism for Persons with Disabilities. A Study from the Perspective of the UN Convention on the Rights of Persons with Disabilities' 166.

<sup>19</sup> Valentina Della Fina, 'Article 4 [General Obligations]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017) 151; CRPD Committee, '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' (2018) UN Doc CRPD/C/GC/7 para 30; Colin Caughey and Hanxu Liu, 'Role of National Human Rights Institutions and Organizations of Persons with Disabilities in the National Monitoring of the CRPD' in Marcia H Rioux and others (eds), *Handbook of Disability: Critical Thought and Social Change in a Globalizing World* (Springer Nature 2021) 4 <[https://doi.org/10.1007/978-981-16-1278-7\\_31-1](https://doi.org/10.1007/978-981-16-1278-7_31-1)> accessed 3 August 2022.

process' as defined in Article 33(2).<sup>20</sup> Lastly, Article 35(4) calls on States to 'give due consideration' to Article 4(3) by inviting OPDs to contribute to the State's Report preparation.<sup>21</sup>

The State's compliance with Article 4(3) could also be determined by its implementation of the first two clauses of the CRPD Article 33. The two provisions require the State to build two sets of institutional architectures: focal points and a coordination mechanism in the government for the Convention's national implementation as specified by Article 33(1); and a framework, including independent mechanisms, for the national monitoring in conformity with Article 33(2). Even though this paper cannot afford detailed discussion, extensive work has been done to interpret these two provisions.<sup>22</sup> Both institutions could be in charge of executing activities ensuring OPDs participated in decision-making processes related to the CRPD implementation and monitoring, including coordinating and contributing to the State Reporting procedure. It is worth mentioning that it is common to designate National Human Rights Institutions (NHRIs) and national equality bodies as independent monitoring mechanisms in compliance with Article 33(2) among European States.<sup>23</sup>

The CRPD Article 35(4) provides the first potential channel for European OPDs to participate in the State Reporting process: through their involvement in drafting the State's Report. Even though it seems that the States are only advised to consult and involve OPDs under this Article, the CRPD Committee have repeatedly recommended such practice and commended that the States have taken action.<sup>24</sup>

OPDs can participate in the preparation processes through the two national mechanisms established under Article 33. In theory and practice, focal points or the coordination mechanism are potentially responsible for the State's Reporting under the CRPD Articles 35 and 36, including coordinating OPDs participation in such process, since it falls into the scope of

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<sup>20</sup> Valentin Aichele, 'Art.33 National Implementation and Monitoring' in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018) 1007–1008.

<sup>21</sup> Stein and Lord (n 11) 696.

<sup>22</sup> See Aichele (n 20) 1007–1008; Luigino Manca (n 6); Gauthier De Beco (ed), *Article 33 of the UN Convention on the Rights of Persons with Disabilities: National Structures for the Implementation and Monitoring of the Convention* (Martinus Nijhoff Publishers 2013).

<sup>23</sup> Caughey and Liu (n 19); OHCHR Regional Office for Europe, 'Study on the Implementation of Article 33 of the UN Convention on the Rights of Persons with Disabilities in Europe' (The Regional Office for Europe of the UN High Commissioner for Human Rights 2011).

<sup>24</sup> Committee on the Rights of Persons with Disabilities, 'Working Methods of the Committee on the Rights of Persons with Disabilities Adopted at Its Fifth Session (11-15 April 2011)' (2011) UN doc CRPD/C/5/4 para 42; Committee on the Rights of Persons with Disabilities, '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' (n 7) para 7; Andrea Broderick (n 16) 136.

'issues relating to persons with disabilities'.<sup>25</sup> The national monitoring framework or independent mechanisms may support the State's Report preparation, since international monitoring is classified as an aspect of the monitoring mandate under Article 33(2).<sup>26</sup> Thus, OPDs could contribute through their involvement in the framework, according to Article 33(3). In any event, the 'full and effective participation' of OPDs in activities related to the State's Report preparation should be ensured by the State following its obligation enshrined in Article 4(3), which entails creating enabling environments for persons with disabilities to organise the OPDs and provide their expertise.<sup>27</sup>

On the other hand, neither the travaux préparatoires of the CRPD nor its text clarified the compliance criterion, especially on the scope of 'closely consult and actively involve' OPDs in Article 4(3).<sup>28</sup> In its later General Comment no. 7 – the core soft law document concerning the participation provisions in the Convention, the CRPD Committee interpreted the essence and implementation of this Article.<sup>29</sup> In the context of European countries under this study, their compliance and practice of this obligation were further elaborated in the Concluding Observations of each State, which will be discussed in the next section.

General Comment no.7 sets out detailed rules and principles widely applied to OPDs participation under the CRPD, including all consultation activities. In the context of the current study, to ensure OPDs participation in the international monitoring activity, including in the preparation of the State's Report, a State needs to consider its obligations in respect of five issues, namely, the national consultation mechanism, the diversity of OPD participants, the provision of sufficient resource and supports, the independence of OPDs, and their access to data.<sup>30</sup> The last three points also have special significance for OPDs to perform reliable

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<sup>25</sup> UNDESA, OHCHR, and IPU, 'Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities' (2007) No 14 2007 95

<<https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities.html>> accessed 26 December 2020. Also see Amnesty International's statement at 7th Session of the Ad Hoc Committee.

<sup>26</sup> Gauthier De Beco and Alexander Hoefmans, 'Chapter One: National Structures for the Implementation and Monitoring of the UN Convention on the Rights of Persons with Disabilities' in Gauthier De Beco (ed), *Article 33 of the UN Convention on the Rights of Persons with Disabilities: national structures for the implementation and monitoring of the convention* (Martinus Nijhoff Publishers 2013) 49.

<sup>27</sup> Virtanen (n 18) 173; Andrea Broderick (n 16) 136; Stein and Lord (n 11) 696. CRPD Committee (n 19) para 7.

<sup>28</sup> See a summary at Andrea Broderick (n 16) 113.

Also see Virtanen (n 18) 169; Sarah Arduin, 'Article 3 General Principles' in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press 2018) 98–99.

<sup>29</sup> CRPD Committee (n 19).

<sup>30</sup> According to FRA, monitoring activities include: 'data collection and analysis; development of indicators and

watchdog roles in the State Reporting procedure, such as submitting alternative reports to the CRPD Committee.

First, a prerequisite for public authorities to have close consultations and allow active involvement of OPDs in all decision-making processes is to establish a nationwide, formal and permanent consultation mechanism. The UN has suggested that States codify mandatory consultation with and involvement of OPDs in all matters related to them through 'institutionalised consultative bodies and mechanisms' to ensure OPDs participation in a timely manner from the initial stage.<sup>31</sup> The Committee further suggests that public authorities in charge of decision-making processes should 'give due consideration and priority' to OPDs 'when addressing issues directly related to persons with disabilities', to avoid a 'tokenistic approach to consultation'.<sup>32</sup> This could be done by informing and explaining the outcome of such processes.<sup>33</sup>

Second, States should respect the diversity of OPDs participated and give special attention to those who work on intersectional issues with women and children with disabilities, in connection with the CRPD Articles 6 and 7. The CRPD Committee further suggests that States to include organisations representing all persons with disabilities of varied backgrounds 'at the local, national, regional and international levels' in consultations and involvements, with particular attention to those groups underrepresented, such as, among others, persons with psychosocial impairments, and neurodiverse persons.<sup>34</sup>

After that, OPDs' participation requires resources and support for their sustainability and needs in accessibility as well as reasonable accommodations. Therefore, the State should provide adequate funding and support to OPDs in consultations and requirements for accessibility and

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benchmarks for assessing progress, stagnation or retrogression in the enjoyment of CRPD rights over time; active involvement in the review by the CRPD Committee of the EU's implementation of the CRPD, including the submission of periodic alternative reports (shadow reports)'. FRA, 'FRA Opinion Concerning Requirements under Article 33 (2) of the UN Convention on the Rights of Persons with Disabilities within the EU Context' (2016) <<https://fra.europa.eu/en/publication/2016/fra-opinion-concerning-requirements-under-article-33-2-un-convention-rights>> accessed 13 December 2021.

<sup>31</sup> UN Human Rights Council, 'Report of the Special Rapporteur on the Rights of Persons with Disabilities (Thematic Study on the Right of Persons with Disabilities to Participate in Decision-Making)' (2016) UN doc A/HRC/31/62 para 66; Committee on the Rights of Persons with Disabilities, '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' (n 7) para 15; Virtanen (n 18) 179–180; Also see examples in Andrea Broderick (n 16) act 137.

<sup>32</sup> Committee on the Rights of Persons with Disabilities, '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' (n 7) para 48.

<sup>33</sup> *ibid* 23.

<sup>34</sup> CRPD Committee (n 19) paras 15, 42,50, 94.s & 94.h.

reasonable accommodations.<sup>35</sup> States are recommended to adopt criteria to allocate funds for consultation.<sup>36</sup> Accessibility and reasonable accommodations should be provided to, among others, all relevant information, communications, and physical environments in the whole process of decision-making.<sup>37</sup>

Funding also has high relevance in securing the independence of OPDs. The Committee repeatedly emphasises States ensure OPDs can seek funding from a wide range of sources, including a formal mechanism of public funding.<sup>38</sup> Instead of requiring OPDs to be registered as a prerequisite for participation in decision-making processes, States should provide free and accessible support to facilitate their registrations.<sup>39</sup>

Lastly, since State Reporting is a monitoring task, it is important for the participants to access appropriate information.<sup>40</sup> Therefore, the data collection should also be conducted in conformity with the CRPD Article 31 and allow OPDs to participate in the data and information collection.<sup>41</sup>

Turning to OPDs' participation at the UN level, CRPD 38(a) provides a legal basis for its Committee to consult with civil society. The CRPD Committee's Working Methods and Rules of Procedures further govern OPDs' participation in State Reporting and other activities within its mandates.<sup>42</sup>

As one of the 'competent bodies',<sup>43</sup> the CRPD Committee welcomes and invites OPDs to contribute to the State reporting procedure, alongside other bodies, including UN bodies and agencies, intergovernmental organisations and NHRIs.<sup>44</sup> Non-governmental organisations, including OPDs, enjoy a series of participation rights in the Committee, among which are submitting written information, such as alternative reports, and initiating or being invited to

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<sup>35</sup> *ibid* 45, 94.i & 94.g.

<sup>36</sup> *ibid* 61. Also see, CRPD/C/BEL/CO/1, para 10, and CRPD/C/GAB/CO/1, para 9.

<sup>37</sup> *ibid* 22.

<sup>38</sup> *ibid* 61,63.

<sup>39</sup> *ibid* 44.

<sup>40</sup> Jerome E Bickenbach, 'Monitoring the United Nation's Convention on the Rights of Persons with Disabilities: Data and the International Classification of Functioning, Disability and Health' (2011) 11 *BMC Public Health* S8.

<sup>41</sup> Luigino Manca, 'Article 33 [National Implementation and Monitoring]' in Valentina Della Fina, Rachele Cera, and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer 2017) 595.

<sup>42</sup> Committee on the Rights of Persons with Disabilities, 'Working Methods of the Committee on the Rights of Persons with Disabilities Adopted at Its Fifth Session (11-15 April 2011)' (n 24) para 1.

<sup>43</sup> UN General Assembly (n 1) Article 36(5) and 38(a).

<sup>44</sup> Committee on the Rights of Persons with Disabilities, 'Rules of Procedure' (2016) UN doc CRPD/C/1/Rev.1 rr 49–54.

varied formal and informal means to interact with the Committee members during the Committee sessions.<sup>45</sup>

These activities are broadly utilised by the OPDs when participating in the State Reporting procedure. For instance, written submissions from OPDs are the source for the Committee's consideration of the State under review and selection of civil society to attend the CRPD Committee meetings.<sup>46</sup> In addition, OPDs have access to the country report, supplementary information under the CRPD Article 36(5), and other openly published material, such as summary records of public meetings for the State's considerations and the Committee's Concluding Observations.<sup>47</sup> These documents provide essential references for alternative report writing.

In harmony with the CRPD Article 4(3) and general principles, the CRPD Committee indicates that, in their work, 'particular value' is given to OPDs' contribution and guidelines with detailed instructions were adopted to ensure their 'timely and appropriate' contributions.<sup>48</sup> The Committee particularly emphasises inclusion, diversity and equality in OPDs participation and the guarantee of accessibility to ensure their effective participation.<sup>49</sup>

Nevertheless, State Reporting is a rather long and complex procedure for local and national OPDs, who sometimes have limited resources, experience and knowledge in the UN systems. International OPD networks, such as International Disability Alliance, have provided practical advice in its handbook to guide such OPDs participation.<sup>50</sup>

### **Key Findings: European Organisations of Persons with Disabilities Involvement in State Reporting processes**

According to the document analysis's result, European OPDs in 18 of 24 examined countries were involved in each State's Report preparation. Among the 18 States, more than half have invited certain OPDs and persons with disabilities to contribute to the preparation through

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<sup>45</sup> Committee on the Rights of Persons with Disabilities, 'Working Methods of the Committee on the Rights of Persons with Disabilities Adopted at Its Fifth Session (11-15 April 2011)' (n 24) paras 43–53; Committee on the Rights of Persons with Disabilities, 'Rules of Procedure' (n 44) 30.3 & 52.

<sup>46</sup> Committee on the Rights of Persons with Disabilities, 'Working Methods of the Committee on the Rights of Persons with Disabilities Adopted at Its Fifth Session (11-15 April 2011)' (n 24) para 23,24 & 46.

<sup>47</sup> Committee on the Rights of Persons with Disabilities, 'Rules of Procedure' (n 44) para 45; Committee on the Rights of Persons with Disabilities, 'Working Methods of the Committee on the Rights of Persons with Disabilities Adopted at Its Fifth Session (11-15 April 2011)' (n 24) paras 3 & 18.

<sup>48</sup> CRPD Committee, 'Annex Guidelines on Independent Monitoring Frameworks and Their Participation in the Work of the Committee on the Rights of Persons with Disabilities' (2016) UN doc CRPD/C/1/Rev.1 para 4.

<sup>49</sup> Committee on the Rights of Persons with Disabilities, 'Rules of Procedure' (n 44). rule 1.2&rule 7.

<sup>50</sup> Committee on the Rights of Persons with Disabilities, 'Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the Work of the Committee' (n 6) app II.

written submissions or hearings.<sup>51</sup> Three States organised open consultations and welcomed commentaries and dialogues with all civil society actors, including OPDs, regarding the Report drafting.<sup>52</sup> Five States combined both approaches by consulting with invited OPDs and receiving contributions from the public.<sup>53</sup> Sweden specifically invited women's organisations to submit opinions, held meetings with people with intellectual disabilities and provided opportunities for children to participate in its Report.<sup>54</sup> In Cyprus and Portugal, their OPDs were encouraged to also submit alternative reports to the CRPD Committee.

Regarding European OPDs' direct involvement in the State Reporting processes, OPDs from 23 countries, apart from Malta, submitted alternative reports to the CRPD Committee.<sup>55</sup> At least 170 alternative reports for all reviewed European countries were submitted to the CRPD Committee, and over 300 European OPDs contributed 61% of these reports. OPDs contributed to 100% of all alternative reports in four European countries.<sup>56</sup>

Most OPD alternative reports were submitted by national disability councils<sup>57</sup> and umbrella OPDs. Some OPDs also chose to form a coalition with other stakeholders for alternative reporting. Some regular stakeholders include the national UN agency, human rights organisations, organisations for persons with disabilities, NHRIs, academics and professionals, and European and international OPD networks. Occasionally, individual submissions were submitted to the CRPD Committee to represent self-advocates, as in the UK and France, as well as representing autonomous regions in a country, as in the case of Spain and Denmark.

Apart from OPDs, NHRIs, national equality bodies and independent mechanisms under Article 33(2), were active contributors to alternative reports. The Committee received written submissions from national human rights bodies from 21 States for each review cycle.

These results suggest that, for the past decade, European OPDs have been active participants in most countries' State Reporting procedures and built partnerships with varied civil society actors on the European and International levels. Despite the efforts made by States to ensure European OPDs' participation in such procedure, document analysis also exposed several common key issues in the full compliance of the State's obligation under CRPD Article 4(3).

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<sup>51</sup> Czech Republic, Denmark, Estonia, Greece, Hungary, Italy, Latvia, Lithuania, Malta, and Portugal.

<sup>52</sup> Austria, Luxembourg, and Slovenia.

<sup>53</sup> Cyprus, Poland, Slovakia, Sweden, and the UK.

<sup>54</sup> CRPD/C/SWE/1, para 4.

<sup>55</sup> This study only considered States have completed one or two cycles of State Reporting by the end of 2021.

<sup>56</sup> Denmark, Hungary, Italy and Slovakia.

<sup>57</sup> The national disability council refers to the national pan-disability coalition OPD that comprises a variety of OPDs and umbrella OPDs, which are often recognised as the national member to represent each Member State at the European Disability Forum.

The first key issue relates to the diverse representation of European OPDs in consultation activities, not limited to activities related to the State's Report preparation. Suppose most examined States only allow selective OPDs and persons with disabilities to the State's Report consultation. In that case, it is unclear to what extent such organisations or individuals can represent the diverse population and needs of persons with disabilities in the reviewed State. In its Concluding Observations, the CRPD Committee repeatedly urged European countries to ensure the participation of OPDs in the scope of Article 4(3) to reflect a broad range of backgrounds, rather than selective involvement, with particular attention on those representing groups experiencing intersectional discrimination.<sup>58</sup> However, as discussed above, only Sweden mentioned attempts to include women and children with disabilities in the State's Report preparation among all 24 countries.

The second key issue relates to inadequate funding and supports provided to European OPDs for their effective participation in decision-making processes. Among all 24 countries, only Luxembourg mentioned the financial contribution to OPDs' alternative reporting activities.<sup>59</sup> In the UK, NHRIs in Scotland, England and Wales, offered funding for OPDs' participation in the country's initial State Reporting through a tender process, while the NHRI faced massive funding cuts and had to cease the existence of its advisory body dedicated to cooperation with persons with disabilities.<sup>60</sup> Several OPDs in the UK (Northern Ireland) and France reported the lack of funding to support their participation in the State Reporting.<sup>61</sup> The CRPD Committee explicated concerns about the lack of support provided for Greek OPDs' alternative reports submission.<sup>62</sup>

Due to the backlog and COVID-19 pandemic, it took an average of 4.6 years for a reviewed European State to be considered by the CRPD Committee. Therefore, sufficient funding is essential for European OPDs to keep updating such information during the lengthy process. Otherwise, such participation entirely relies on the 'goodwill' of OPDs and their 'full and effective participation' enshrined in the CRPD will 'remain greatly diminished'.<sup>63</sup> In some cases, it was challenging for OPDs to develop and report in the collective shadow reporting attempt without proper support from the government, as the Committee noted in its Concluding

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<sup>58</sup> CRPD/C/ITA/CO/1, para 8; CRPD/C/DEU/CO/1, para 9; CRPD/C/POL/C/1, para 5.

<sup>59</sup> CRPD/C/LUX/1, para 414.

<sup>60</sup> Scotland NGOs CRPD Shadow report (2016); Alternative Report of United Kingdom Independent Mechanism (UKIM) (2017); Alternative Report of Members of the United Kingdom Independent Mechanism (2017); UK Disability Action-Shadow Report(2017); and Disability Rights UK and Disability Wales-CRPD shadow report(2016), 6.

<sup>61</sup> Alternative Report of Deaf and Disabled People Northern Island (2017); Advocacy France submission (2019); Arrêt Traitements Forcé (ATF)-formerly "Depsychiatriser", 13 (2021)

<sup>62</sup> CRPD/C/GRC/CO/1, para 48.

<sup>63</sup> UK Disability Action-Shadow Report, 49-50.

Observations regarding Denmark on Greenland.<sup>64</sup> In an extreme case, the UK Disabled People's Council, a former national umbrella OPD, which worked as the main contact point in the disability movement with the UK Government during the initial stage of the State Reporting, <sup>65</sup> faced financial hardship and had to close down in 2015, before the Committee reviewed the country.<sup>66</sup>

Flaws in resource allocation to OPDs could compromise their independence from the State and thus affect their watchdog role when participating in monitoring activities. For instance, smaller OPDs in France described their difficulties in seeking funding to carry out advocacy activities, whereas some disability organisations are dependent on State decisions regarding their appointment and funding.<sup>67</sup>

The last key issue reflects the lack of access to data. OPDs reported that this issue hindered their ability to participate in monitoring activities, either due to databases managed by public authorities were not public to the OPDs as in Hungary,<sup>68</sup> no availability of statistics and disaggregation of information regarding persons with disabilities, as in some regions in the UK (Northern Ireland) and Denmark (the Faroe Islands and Greenland),<sup>69</sup> or such statistics stored in inaccessible databases, as in Denmark.<sup>70</sup>

Taking into consideration the legal interpretation in the last section, other issues relating to the consultation mechanism may require further attention from the European States to ensure OPDs full and effective participation in State Reporting processes. For instance, only a few States provided concrete examples of the give due consideration to OPDs' contributions in consultation, including Poland, which provided feedback on NGO comments on the draft the State's Report, and Latvia's Report made reference to several OPD reports.

## **Discussion and conclusion**

Legal doctrinal and empirical research findings indicate that the normative framework and States' obligations defined in the CRPD Article 4(3) are not only relevant for European OPDs' participation in decision-making processes related to national implementation and monitoring of the CRPD, but also provide the foundation for their 'full and effective' participation in the State Reporting procedure under Article 35. OPDs' participation in such procedures, especially with submitting their alternative reports, play a significant role in facilitating the CRPD Committee's monitoring function and is protected by detailed UN rules and guidelines.

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<sup>64</sup> The Danish Institute for Human Rights-Parallel report on initial report of Denmark (2014), 17; Alternative Report of Disabled Peoples Organizations-Denmark, 2; CRPD/C/DNK/CO/1, para 11.

<sup>65</sup> See CRPD/C/GBR/1, para 39 and Annex III.

<sup>66</sup> See Disability News Service, 'UKDPC "Fends off Insolvency"' (Disability News Service, 28 February 2014) <<https://www.disabilitynewsservice.com/ukdpc-fends-off-insolvency/>> accessed 13 August 2022.

<sup>67</sup> Alternative Report of Advocacy France (2021), 5.

<sup>68</sup> Alternative Report of NGO Coalition of the Rights of the Child (2017), 21

<sup>69</sup> UK Disability Action-Shadow Report (2017), 57; Danish Institute for Human Rights submission (2019), 10; Alternative Report of Faroe Islands Union for the Handicapped (2014), 1.

<sup>70</sup> Joint Submission - 38 Danish Civil Society on Denmark (2014), 57

Not all 24 examined European States showed evidence of consultation with and involvement of OPDs when drafting the State's Report, against the recommendation of the CRPD Committee. Considering the Report is an important issue relating to persons with disabilities and monitoring activities, it is the State's obligation to provide opportunities for OPDs to be consulted with and involved for full compliance with the Convention. Such a participation channel could be important for OPDs who have no expertise or resources in producing separate alternative reports and provide a platform to exchange dialogue on the CRPD's national monitoring. However, it is up to the OPDs to decide whether to participate in such activities or perform the independent assessment for the State Reporting procedure. In some of the examined countries, OPDs have participated in both activities.

Moreover, the 'full and effective participation' of OPDs in the State Reporting procedure could be influenced by the public authorities' implementation of their obligation under Article 4(3), such as the diversity of OPD participants, sufficient and independent funding allocated to OPDs and their access to data for monitoring activities. A State needs to pay particular attention to the uneven implementation of the CRPD and the development of OPDs among self-governed regions.

For OPDs who decide to participate in the State Reporting procedure, they could seek support and build alliances with national, regional and international civil society actors, especially NHRIs and international OPD networks, who have shown great commitment, experience and resource in supporting OPDs in the previous State Reporting processes among examined European countries.

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