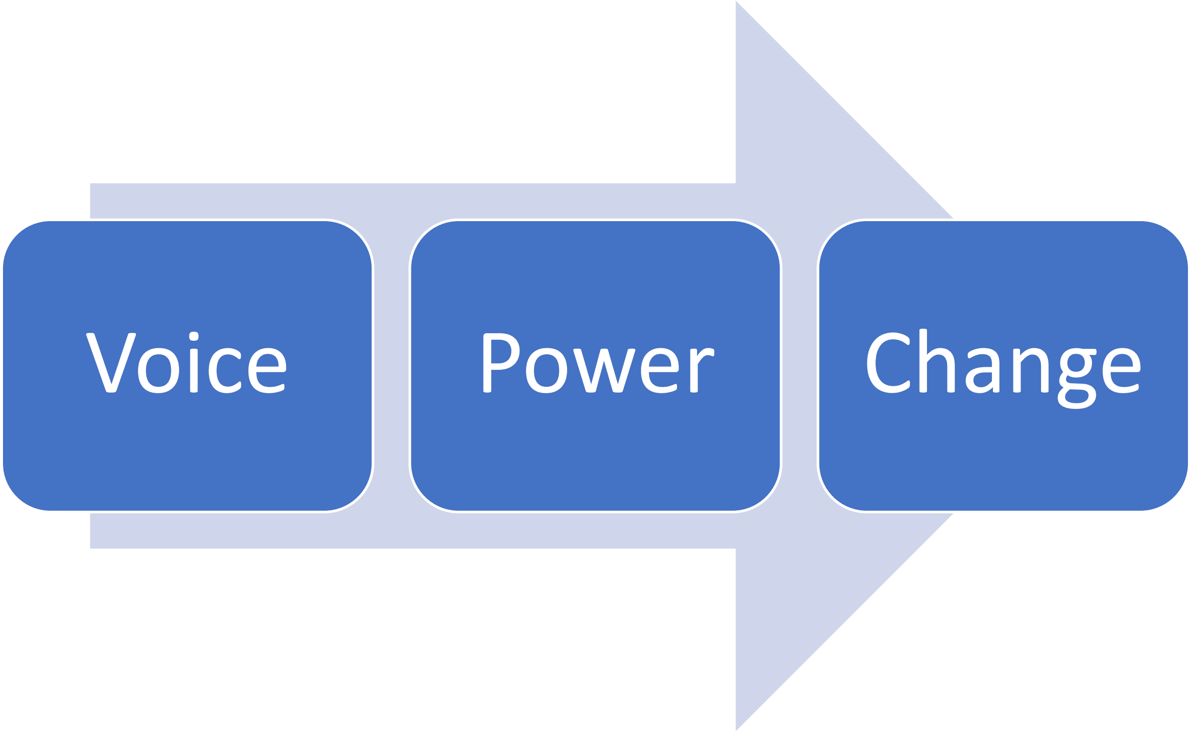
Ref. Ares(2020)5156514 - 01/10/2020

DARE
Disability Advocacy Research in Europe

Disability advocacy research in Europe: emerging insights

Year 1 Research Report



Project Acronym: DARE

Title: Disability Advocacy Research in Europe

Grant Agreement: 814249

WP3 (Research) Deliverable D3.3

University of Leeds, on behalf of the consortium Research Committee

ject has received funding from the European Union’s Horizon 2020 research and innovation
mme under the Marie Skłodowska-Curie grant agreement No 814249.

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This Research Report is provided by the Research Committee to showcase the emerging research of the 14 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 first year. These chapters are based on literature reviews, preliminary legal research, background policy research, theorising, methodology, and other preparatory desk research establishing the base for their research (examples from their research findings may be the subject of future research report publications in Year 2 or Year 3).

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1 Disabled children's participation in healthcare decision-making

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Abstract

The UN Convention on the Rights of the Child (UNCRC) has contributed to the proliferation of national child rights laws and policies which aim to ensure the participation rights to children including in the area of healthcare decision-making. Children are not endowed with full autonomy and legal capacity as adults and their consent to medical treatments remains limited by referring to their 'evolving capacities', immaturity, or irrationality. The age of the child is too often used as a proxy for a child's maturity (status approach) which establishes the disputed correlation between the child's age and his/her decision-making capacities. Turning to the assessments of children's capacities and competence (functionality approach) instead of on child's age may also be problematic especially for disabled children due to focus on child's individual capacities as disabled children may experience 'failure' to reach the standards of 'normal' development. This article builds the argument for relational and context-dependent understanding of children's capacities and competence on the basis of comparative international human rights law analysis exploring the divergences and synergies between the UNCRC and UN Convention on the Rights of Persons with Disabilities (UNCRPD). It argues that the focus should shift from children's competence for decision-making towards the competence of adults to provide age-appropriate and disability-related support to disabled children to participate in healthcare decision-making. Impairment-related health interventions may warrant special attention in best interests assessments due to their complexity, uncertainty of outcomes and the pursuit of normality by adults.

Introduction

The UN Convention on the Rights of the Child (CRC) has given high visibility to children's rights discourse and has challenged the traditional understanding of childhood and the views of children as the objects of adults' concerns (Lundy, 2007; Hinton, 2008; Holzscheiter, 2010). Children's participation often remains restricted or denied in policy or practice, leaving children with little or no influence over decisions in the area of healthcare which impact their lives in profound ways. Disabled children are routinely excluded from healthcare decision-making both through policies and practices which often require either threshold age or threshold competence assessed by health professionals to make decisions around medical treatments. They are excluded both due to their status of children and because of disability (Lansdown et al., 2013).

This paper offers a critique of both the age-based and competence-based criteria for participation in healthcare decision-making and advocates to shift the attention on the role of adults to provide age-appropriate and disability-related support to disabled children in the healthcare decision-making processes.

Children's participation in healthcare decision-making

The medical consent, as seen by bioethicists, is the embodiment of autonomy and results from independent decisions made without the interference of others (Miller and Wertheimer, 2010) which poses a particular difficulty for children in exercising their participation rights.

Individualistic conceptualisations of autonomy based on the person’s cognitive abilities and competencies for independent decision-making effectively deprive children of the possibility to consent to medical intervention and entrust the responsibility of decision-making in the context of health choices to adults.

However, participation in healthcare decision-making can not be reduced to consent to medical treatment. Rather, the participation can include different levels of being involved in making the decision, namely: being informed, expressing an informed view, having the view being taken into account, being the main decision-maker (Alderson, 1996). Health laws that regulate consent are mainly concerned with identifying the main decision-maker and are using age-based and competence criteria to restrict children’s decision-making powers (Lansdown, 2005). Following section will critically analyse the jurisprudence of the UN Committee on the Rights of the Child (CRC Committee) in order to obtain an insight into the international human rights law’s take on this topic.

Children’s participation in healthcare decision-making and the CRC

Children’s participation as the principle of the CRC and the right enshrined in its Article 12 is not to be understood as a “momentary act, but the starting point for an intense exchange between children and adults…” (Committee on the Rights of the Child, 2009, para.13), so even if the adults do retain the ultimate decision-making powers on a particular issue they have the responsibility to involve children as the participation is guaranteed both as a substantive and procedural right.

CRC Committee recommended and welcomed the introduction of legislation which sets the fixed age for giving the consent for medical treatment (Committee on the Rights of the Child, 2009; Committee on the Rights of the Child, 2016). It also recommended to ensure that the views of younger children are given due weight if they are able to demonstrate the “capacity to express an informed view on her or his treatment” (Committee on the Rights of the Child, 2009, para.102).

This approach of the CRC Committee points out to several apparent inconsistencies. First, if the CRC Committee acknowledged that the “age alone cannot determine the significance of a child’s views”, then its encouragement of the States Parties to introduce legislation which sets the fixed age for child’s consent to medical treatment represents a departure from this position and from the reading of the phrase “in accordance with the age and maturity” from the first paragraph of Article 12. The age itself is not a marker of maturity but a proxy for it as “individual children reach maturity at different ages” (Committee on the Rights of the Child, 2016), so using the age-classifications can always be either over-inclusive or under-inclusive meaning that some children who are not yet mature enough will be entitled to exercise the right as they reached the prescribed age while some younger children who are mature and would potentially be able to exercise it are prevented of it by the fact that they are still young (Godwin, 2011).

There are two identifiable lines of reasoning for the expressed support of the CRC Committee for age-based classifications. One possibility is that the Committee considers the medical treatments as a highly sensitive area of decision-making with the potential to cause children irreparable harm if they refuse to undergo the treatment so it considers important to limit the possibility of children’s autonomous consent to protect them from harm. This reasoning would be in line with ‘caretaker perspective’ of children’s rights which is driven by the imperative to act in the best interests of the child seeing the child as weak and vulnerable and in need of protection and socialisation (Dillen, 2006). However, if by the introduction of age-classifications adolescents who have not reach sufficient maturity to understand the nature, consequences, and alternatives to a proposed treatment but have reached the prescribed age, are allowed to consent independently without having to undergo capacity assessment they might experience the risk of harm. On the other hand if the Committee by recommending age-classifications wanted to enhance children's participation in healthcare decision-making which would correspond to 'child liberator perspective' seeing children as agents and rights-holders (Dillen, 2006), does it not exclude from the possibility to consent all those children which have acquired sufficient maturity and competence but have not yet reach the age? In any case, using the age as a sole criterion is at least dubious means for achieving any of those two objectives.

The second inconsistency concerns the Committee's recommendation for younger children's views to be given due weight if the child is able to demonstrate "capacity to express an informed view on his or her treatment" (Committee on the Rights of the Child, 2009). This interpretation places the burden of proof of capacity to a child, thus departing from the earlier claim of the Committee in the same General Comment that "it is not up to the child to first prove her or his capacity". Further, the requirement to "express an informed view" departs from the text of the Article 12 relying on additional qualifier - "informed", which imposes a heightened standard for the child's views in the area of healthcare decision-making which makes it easier for adults to discard child's opinion as uninformed and override it without even taking it into consideration.

The positive development for the participation of adolescents in healthcare decision-making is a recommendation of the CRC Committee that the "voluntary and informed consent of the adolescent should be obtained whether or not the consent of a parent or guardian is required for any medical treatment or procedure" (Committee on the Rights of the Child, 2016, para.39). Still, further analysis is required to determine whether or not this includes an effective possibility for the adolescent to refuse the treatment. The ruling in the landmark Gillick case from 1985 in England (Gillick v West Norfolk and Wisbech AHA [1985] 3 W.L.R. 830[1986] A.C. 112, 1985) entitled children under 16 to consent to medical treatment if they exhibit 'sufficient understanding and intelligence' (Freeman, 2006). However, subsequent case-law represents a retreat from Gillick ruling in so far as it entitled children with the right to consent to medical treatment but not with the right to refuse it (Freeman, 2006; Cave, 2014). Nevertheless, Gillick's case ruling represented understanding that the age as a sole criterion may not be enough to justify the restrictions of a child's participation in healthcare decision-making. It intended to move away from status-based to functional approach by focusing not on a child's age but a child's competence for decision-making. It is why I will turn now to the concepts of capacities and competence for healthcare decision-making to understand if and how they contribute to enhancing or impeding the children's participation in healthcare decision-making.

Children's competence for healthcare decision-making

The way how the capacities and competence of children are understood, assessed, and by whom plays an important role to understand how the laws, policies, and practices in the field of healthcare decision-making could work to include or exclude children from the enjoyment of their participation rights in this domain. Alderson asserts that the competence of children to make health-care decisions includes the following elements: ‘understanding the proposed treatment, being able to make a wise decision and being free from coercion’ (1993). The problem with such individualistic conceptions of competence lies in the fact that it is conceived and defined based on adults’ gold standard (Mårtenson and Fägerskiöld, 2008). Moreover, there is no test to assess the competence so ultimately it comes down to the subjective judgements of health professionals to determine if the child is competent or not (Moore and Kirk, 2010).

Beauchamp and Childress describe decision-making competence as an ‘ability to perform a task’, that is to reach a decision based on a sufficient level of understanding (2019). According to them, competence as an element of informed consent includes the understanding of the nature of proposed treatment and it’s risks and benefits, the consequences of treatment’s refusal, and available alternatives (Beauchamp and Childress, 2019).

Such an understanding of competence is an individualistic one based on cognitive abilities and as such has disempowering potential for all children and particularly disabled children (Davis and Watson, 2000). Tisdall warns against the lack of conceptual clarity of children’s capacities and competencies which pervade laws and practices being used by adults to justify restrictions of children’s participation and yet they remain contested and rarely defined (Borgne and Tisdall, 2017; Tisdall, 2018; Moran-Ellis and Tisdall, 2019).

In the context of healthcare decision-making participation of children is highly dependant on adults, namely health professionals and parents/carers. Hinton writes about ‘competence bias’ if adults see competence as a threshold criterion for participation and restrict child’s autonomy based on assumed lack of competence underpinned by the developmental paradigm of ‘evolving capacities’ (2008).

It follows that the link between the capacity and competence on one side and autonomy on the other is said to be such that the capacities serve as a “gatekeeper” to autonomy (Ruhe et al., 2016). These capacity criteria are based on cognitive abilities residing with individuals. If children’s cognitive abilities are perceived as yet-not-fully-developed, undergoing the process of maturation, the ground for denying them autonomy is their status of being children (Ruhe et al., 2016). The relational approaches to autonomy originating from feminist philosophy acknowledge that the fact that people are embedded in the social relationships affects the formation of their identities, values, objectives and commitments (McLeod and Sherwin, 2000; Mackenzie and Stoljar, 2000; Holroyd, 2009). What is common for all strands of the relational autonomy derived from the feminist scholarship is that none of them rejects the importance of cognitive abilities and their role in the process of deliberation. Rather, they emphasize the importance of additional consideration of the role of contextual factors and social relationships that the person is embedded in, in forming personal preferences and choices. For the autonomy of children, the problem lies exactly on the side of child’s (evolving) capacities and cognitive abilities which justify the limitations of children’s autonomy.

Ruhe (2016) and others apply relational approaches to autonomy of children to reconceptualise children’s decision-making capacities. The focus of the concept of relational capacity moves from the individual child to significant others in child’s life such are the parents and physicians in the context of health care. They argued that the capacities do not reside in the child but develop "through communication, explanation, and interaction with others" moving away from an understanding of capacity as originating strictly from cognitive abilities (Ruhe et al., 2016). The participation of children is contingent on the recognition of and support for a child's autonomy and agency by adults and their willingness to share or confer decision-making powers to children (Coyne and Harder, 2011; Sandland, 2017) and it is why I now turn to explore their role in providing the support to children to participate.

The role of adults in children's healthcare decision-making

The power, as being 'multidirectional and alinear' (Sandland, 2017) is embedded in the relationships between all the actors included in healthcare decision-making: child-parent, parent – health professional, a health professional – child. Thus, examining the attitudes of all of these actors and their professional or parenting practices contributes to understanding of the contextual factors of children's participation in healthcare decision-making which reside outside of children's individual decision-making capacities.

It was argued in prior sections that the participation rights of children entail a positive obligation for parents to support the child towards autonomy and enhanced responsibilities (Betzler, 2015; Ruhe et al., 2016). Dillen is referring to possible tension between the caring responsibilities of parents and the participation rights of children. She advocates that the resolution of this tension may lie in the "theory of responsibility through and for the other" whereby parental responsibilities extend beyond care and protection to support to child's increasing responsibilities (2006). She further advocates for an alternative view of parent-child relations which is not based on the struggle for power and autonomy but centers on human connectedness and 'heteronomous appeal to responsibility' where the child as an active agent sends the ethical appeal to parents and calls for their responsibility while they, in turn, provide not only the care and protection but a stimulus for child's responsibility (Dillen, 2006).

While the rights discourse may regard children as non-autonomous and incapable of independent decision-making the idea of human connectedness reveals the importance of parental guidance but at the same the importance of partnership and trust between parents and a child. The participation of the child is not an obligation but the matter of child's choice and parents have the responsibility to be proactive and engage the child in deliberations in important matters to the extent that the child feels comfortable with.

The debate on protection versus autonomy is central for considerations of children's healthcare decision-making as the adults including both professionals and parents may be reluctant to share with children full information related to risks and harms associated with treatment due to the perception of children as immature and easily frightened so that the fear might lead to the refusal of the treatment (Alderson, 1993). However, in the Alderson's study of children's consent to elective orthopedic surgery, the most of the children said that they wanted to be informed on both benefits of the treatments and associated risks and harms as it helped them to accept the need for surgery and to manage their expectations and cope with the treatment and recovery while withholding the information created the space for irrational fear and mistrust (Alderson, 1993).

Therefore, shifting the focus from children's capacities and competence to competence of adults to provide accessible information and support to children to participate represents the move towards a relational understanding of capacities, competence and autonomy and as such has special importance for disabled children who may require both age-appropriate and disability-related support to participate in decision-making.

Disabled childhood, autonomy, and participation in healthcare decision-making

The analysis of the construction of disabled childhood should involve critical reflections on the emergence and hegemony of the concept of ‘normalcy’ and ‘normal’ development of the child. The ‘normal’ development of the child rests on the prescribed normative path of childhood development and certain milestones that the child should reach across the multiple fixed stages of development (Cooper, 2013; Mallett et al., 2016; Goodley et al., 2016). The failure of disabled children to comply with the stages of ‘typical’ development constructs them as ‘abnormal’ as opposed to the prescribed standards of able-bodiedness (McRuer, 2006). Thus, the notion of individualized autonomy resting on the individual capacity for reasoning and reaching rational decisions compounded with the perceptions of abnormality attributed to disabled children serves to deny them the competence to exercise their agency.

While the medical professionals may feel urged to suggest the treatments which aim to fix, mitigate or alleviate the impairment resulting from the impetus to ‘do something’ (Parens, 2006; Cooper, 2013), it is important that in the considerations of impairment-related treatment options medical professionals include disabled children when determining their best interests. The disabled child may not consider his/her body as abnormal but may develop the wish for normalization after the continuous exposure to discrimination, segregation, and rejection by others who perceive it as abnormality (Cooper, 2013). The child’s refusal to accept the normalizing treatment and preserve his/her identity may be wrongly interpreted as the absence of reason or competence (Alderson, 1996). On the other hand, disabled child’s wish or the wish of parents to pursue the normalizing treatment may result from the internalized ableism (Campbell, 2008) or the prospects of improving the social conditions of family life (by reducing parents’ caring responsibilities) (Parens, 2006). Therefore, the process of informed consent has to include an intense exchange between the medical professionals, parents, and disabled children and to carefully inform on and evaluate potential hopes and benefits and risks and harms in order to reach the decisions based on the best interests of the child.

Parents may know very little about the impairment and disability especially if their child was recently diagnosed so they tend to regard medical professionals as an authority who holds the knowledge of disability whom they can trust to decide on their child's best interest (Murray, 2000). The power imbalance poses an additional challenge for parents and children to contradict the views of medical professionals. If the professional's view gets challenged then the professional's knowledge and authority are brought into question and if the medical professional is the one to assess the child's competence in the informed consent process it poses the risk that the child would be found incompetent and his/her wish overridden.

A functional approach to competence assessments that assesses children’s decision-making capacity and level of understanding may have a particularly adverse effect for disabled children whose ability to communicate, make independent choices, or weigh alternatives may be compromised by both personal and environmental factors which play together to construct disability. Disabled children are often deemed as lacking the capacities that other non-disabled children may have acquired and incapable of developing their decision-making competences (Priestley, 1998; Davis and Watson, 2000; Della Fina et al., 2017). Disabled children's development of capacities and acquisition of competence may significantly differ from their peers due to various reasons such as higher exposure to violence, exclusion from education, institutionalization, compromised health, or lack of support services, to name the few (Batshaw et al., 2007). This is why they are facing with an increased likelihood of parental overprotection and greater exclusion from decision-making processes including identified disregard of their views and consent in the context of medical treatments (Della Fina et al., 2017).

The onus in disabled child capacity assessments should thus be placed on the context identifying the types of support provided to a child in order to maximise his/her capacities and develop skills for collaborative decision-making (Ruhe et al., 2016). The adults should critically reflect on their own attitudes in this process which can cloud their judgments of child's best interests and engage in intensive exchange and mutual deliberation with the child including the provision of peer support where relevant, rather than imposing paternalistic intervention without child's agreement.

If the child's capacities are regarded as a gatekeeper to autonomy, then a relational understanding of capacities opens the possibility for critical examination of the grounds for restrictions of children's autonomy both in law and practice.

Conclusion

It is recognized that an array of barriers limit disabled children's participation in decision-making processes that affect them (Hammarberg, 2007; Hinton, 2008; Lansdown et al., 2013). Many of these barriers originate within policies and practices which exclude children's voices from adult-led considerations of their 'best interests'. The legal restrictions of children's participation based on children's age, normative development stages, cognitive abilities and presumed incompetence are widespread globally (James, 1998; Fortin, 2009).

Relational understanding of children's capacities and competence for healthcare decision-making acknowledges the role of contextual factors and adults in fostering and developing children's capacities. It shifts the burden of proof to adults as they are tasked with the responsibility to support the development and exercise of child's capacities and not merely discard child's view based on incompetence. The influence of adults' motivations, attitudes, and beliefs or parenting styles and relations towards a child is reflected upon critically in the process of best interests determination enabling to shed the light on possible oppression of children coming from adults. Finally, in the case of conflicting views between a disabled child and adults, it promotes further engagement to reach the consensus rather than simply overriding the child's view.

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2 Violence, gender and disability: cultural understanding and access to justice

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Abstract

Even though it is framed as a human rights concern violence against disabled women remains largely invisible and not acted upon by authorities. This article emphasises the complexity of violence and disability and highlights the importance of understanding the cultural, social, historical, political, legal, and economic contexts in which gender-based violence against disabled women occurs. In doing so, the article draws theories from the social model of disability, anthropology of violence, and the human rights model of disability. First it discusses the social model of disability and its natural affinity with understandings of structural violence offered by the anthropologist, Johann Galtung (1969), while arguing that such understanding helps to see the violence applied toward disabled people more clearly, as opposed to the language of barriers, inequality and exclusion. Building on from this, the paper highlights how the human rights approach to disability goes beyond social and cultural approaches by demanding full disability equality and the recognition of the discrimination resulting from the intersection of disability and gender, which is captured in the right of disabled women to live free from violence and to prosecute the violence they experience. After providing a brief literature review and discussing the lack of access to justice for disabled women, the article concludes by calling for new research taking into account all the complex forms, contexts and approaches, creating and legitimating this violence.

Introduction

Violence is a concept that takes many forms and shapes. As argued by Scheper-Hughes and Bourgois (2004) violence ‘can be everything and nothing; legitimate or illegitimate; visible or invisible; necessary or useless; senseless and gratuitous or utterly rational and strategic’ ((Scheper-Hughes and Bourgois 2004, p. 2). Depending on the society and its political position in the global economic and political scale, some acts may be constructed as violence, or simply as a culturally defined legitimate expression of authority, as a conduct that is socially permitted, or as an act that is encouraged as a moral right or duty. These socio-cultural constructions of violence and ideologies of what it is or not, influence and shape our understanding of violence and how we express it within our cultural environments. The cultural implications of how we understand personhood, dignity, self-worth, or value in or within our societies, shape our ways of framing concepts like gender and disability within our societies, and the construction of violence around these concepts and their intersection. As argued by Weber (2009, 2012) race, class, gender and sexuality are social systems of oppression that change over time and across cultures, and are negotiated and contested every day in social relationships in order to preserve the privilege of some groups over that of others. In sustaining such power and social control, violence is produced and reproduced. Due to multiple and intersecting forms of discrimination on the basis of gender and disability, and possibly other factors like race, class and religion, disabled women face and are exposed to multiple systems of oppression (Barrett and co., 2009). Thus, being both disabled and a woman causes a power imbalanced social status in most cultures (Hague, Mullender and

Thaira, 2011). Understanding disability, therefore, means being aware that how disability is viewed, perceived and experienced is cross-culturally different, and which can lead to disabled people being situated differently and subject to multiple and different types of gender-based violence.

Even though it is framed as a human rights concern (Didi et al., 2016; FRA, 2014), violence against disabled women remains largely hidden, undetected and not acted upon by authorities. Limited research has focused on the access to justice for disabled women who have been subjected to gender-based violence. There are increasing calls for greater understanding, knowledge, protection, public awareness, and measures to end this violence (AHRC, 2018; Dowse, et al, 2013). To do so, this paper argues that we must look at how we understand and deal with gender-based violence against disabled women, which is culturally, historically, socially, legally, economically, and politically shaped within our societies. To this end, this article will emphasise the cultural contexts in which gender-based violence against disabled women occurs. First it will discuss disability and violence, drawing attention to the social model of disability and its natural affinity with understandings of structural violence offered by the anthropologist, Johann Galtung (1969). This will be followed by a discussion 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. Finally, a brief literature review will highlight the lack of access to justice for disabled women, while concluding by calling for research on disability and violence that takes into account all its complex forms and contexts in order to create knowledge, understanding advocacy to end this violence.

Disability and violence

Tom Shakespeare has argued that there is a "family of social-contextual approaches" to disability (Shakespeare 2006, p. 28). The social model of disability provides a basis for understanding disability as resulting from a historical, material and social conditions, which create a disabling society that marginalises and excludes disabled people (Oliver, 1996; Thomas, 1999; Randolph & Andresen, 2004). As summarised by Traustadóttir, the social model focusses on the social context and environment; emphasises social barriers and the relationship between the individual and society; views discrimination, exclusion and prejudice as the problem; while ending discrimination, segregation and removing barriers is the answer (Traustadóttir 2009, p. 5). Goodley (2011) states that the social model focused on the causes of disabled people's exclusion 'through social, economic, political, cultural, relational, and psychological barriers' (Goodley 2011, 11–12). Hence, this makes disability a form of social oppression (Oliver, 1996; Randolph & Andresen, 2004). Despite the variations of the social models, its underlying premises are useful for developing an approach to theorising about disabled people and their experience of violence. Many scholars have used the disability theory derived from the social model of disability and build upon their analyses of the understanding of the way disablism is produced and shaped by other dimensions, i.e. gender, in an attempt to conceptualise, understand, and connect the concepts of disability and violence.

For example, the study by Chouinard (2012) in Guyana, uses and argues for a social model materialist theory of disability to conceptualize links between violence and disability, and recommends the psycho-analytic theory as a tool to make sense of why non-disabled people engage in violence toward those with impairments, in this context constructing disabled people as 'deserving' of violence (Chouinard 2012, p. 789-790). She concludes that domestic violence shaped disabled people's struggles for inclusion and well-being: for both those who became disabled as a result of domestic violence, and those who suffered domestic violence as a result of being disabled (ibid). These experiences highlight barriers to inclusion as a result of the structural violence of Guyana's place within an unequal global capitalist order, disabling conditions of life by acts constructing disabled women as a woman deserving of male violence, and constructing the disabled other' as dis-entitled to rights enjoyed by non-disabled persons in the home (ibid). Violence, therefore, is conceptualised as unfolding across geographic scales, from the global to the intimately personal, and as partly manifest in outcomes of poverty (Cassiman 2007), while acknowledging that experiences of disability are embodied and that experiences of violence have physical, psychological and emotional repercussions at the intrapersonal scale (Chouinard 2012, pp. 780-90). Another article that emphasises poverty, together with gender relations and disablism, while specifically focussing on the domestic violence against disabled women in Australia, was written by Mays in 2006. Using the social model and integrating material feminist interpretations, Mays argues that in order to theorise about disabled women, we need to analyse the social relations and position of disabled women in relation to material conditions and ideological dimensions of oppression, which results in violence against women (ibid). By investigating the interrelations between differing forms of oppression, we can identify insights into the way in which disabled people experience violence as consequences of marginalisation. Overall, both of the above studies write about violence by mainly concerning the barriers faced by disabled women to inclusion, including poverty and lack of access to employment, training, assistive devices, stigma, stereotypes, aspects of independent living, and experiences of violence in the everyday life. This conceptualisation of violence by the social model of disability has a natural affinity with understandings of violence offered by the anthropologist, Johann Galtung (1969), which helps us to see the violence applied toward disabled people more clearly, as opposed to the language of barriers, inequality and exclusion.

Disability and structural violence

Galtung (1969) provides us with a kind of foundation of where and how structural violence came from. Despite the fact that the article is written a few decades ago, many of his arguments are still of importance to understand one particular form of violence: structural violence. He states that "violence is present when human beings are being influenced so that their actual somatic and mental realizations are below their potential realizations." (Galtung 1969, pp. 167-191). By this he means that because certain structures are in place (for example not having access to clean water) this will have effects on the body, results in people suffering an indirect systemic violence. Referring back to the above studies, when disabled women do not have adequate income to reach their potential, do not have enough income to get food or their medication, do not have accessible housing, assistive technologies, or accessible employment and training facilities, they cannot reach their potential in improving their conditions of everyday life. Due to the structures in place that deny such resources, this will result in the disabled women suffering all types or a combination of physical, psychological, social, economic, legal, and cultural violence within their societies. Hence, this leads to them being violated by the structural frames that denies such opportunities in order to reach their potential. Even though "there may not be any person who directly harms another person in the structure. The violence is built into the structure and shows up as unequal power and consequently as unequal life chances." (ibid). Galtung does not refer to individual misunderstandings here, but rather to the patterns in the society that cause the power balances leading to violence, which sometimes people are not even aware of that it is happening. This leads to structural violence being understood as systemic violence as involving everybody, which makes it hard to point to who's fault or who to blame for the violence suffered. Therefore, in order to understand structural violence, the lack of clear subject-object relationships is important (ibid).

Structural violence, therefore, can be conceptualised by looking firstly at the cultural understanding of violence that evolves and results from the mix of the historical, social, economic, cultural, legal, and political aspects of a given society, and secondly looking at how violence is understood, framed, expressed and reproduced by the individual member and the entire group of that society. Bringing these two aspects together highlights structural violence to be understood as the manifestation of the disadvantages faced by people who live in poverty or of those who are marginalized as a result of racism, disability, gender inequality, or a combination of these factors. Hens, when looking at gender-based violence from the anthropology point of view, we need to combine its numerous manifestations and not just one dynamic of such type of violence and consider everyone including women as reproducers of violence.

Violence and the Human Rights Approach

The adoption of the United Nations Convention on the Rights of Persons with Disability (CRPD), introduced a paradigm shift towards a new understanding of disabled people (Degener 2016). 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). The intent of the CRPD was not to create new law, but to clarify existing international human rights law to the situation of disabled people and explicitly reiterates their standing as human rights holders (Arnarsdóttir, 2009; Quinn, 2009). Thus, the Convention encapsulates a human rights perspective on disability and uniquely combines it with the social perspective (Degener, 2016; Kanter, 2007; Quinn & O'Mahony, 2017), making a deliberate attempt to align civil and political rights with an emphasis on social justice, which includes a focus on economic, social and cultural rights (Quinn & Flynn, 2012). By taking this stand, the human rights approach goes beyond the reach of the social approach, providing additional means of reaching the goal of full disability equality and fundamentally changing the position of disabled people from recipients of welfare to having entitlements (Degener, 2016; Kanter, 2015; Office of the High Commissioner for Human Rights, 2010; Stein & Stein, 2007).

Despite the shared aspects between the social model and the human rights approach to disability, particularly the understanding that society bears the chief responsibility for creating barriers that disabled people face, Degener (2016) maintains that the differences are significant and warrant that the human rights approach should be regarded as representing a new and a distinct model on disability. She identifies six factors that separate the two models, including the recognising of impairment as a contributing factor to creating disability and call for its inclusion in developing full disability equality (Degener, 2016, p. 11). A key factor, Degener points out, is that not only does the human rights model regards rights as the foundation of disability policy but, unlike the social model, it provides "moral principles or values" as its foundation (Degener, 2016, p. 4). In addition, unlike the social model, the human rights model includes a clear recognition of the "different layers of identity" (Degener, 2016, p. 10), recognizing the aggravated forms of discrimination often faced by persons with disabilities on the basis of the combination of disability with other factors, including sex, race, religion or age (Degener, 2017). In the context of this article, it would be the recognition of the discrimination resulting from the intersection of disability and gender faced by disabled women. Such discrimination leads to violence, which is defined by Allen (2001) as '… from one that concentrates on criminal acts toward people or property to one that includes discrimination, economic inequality and social injustice' (Allen 2001, p. 47). As she outlines it: 'This definition of violence includes harm that is socially sanctioned and avoidable actions that violate one or more human rights or prevent the fulfilment of a basic human need' (Allen 2001, p. 4). Hens, gender-based violence against disabled women is the outcome of the violation of the right to freedom from violence and access to justice as called for by Articles 6 on Women and girls with disabilities, 13 on Access to justice, and 16 on Freedom from exploitation, violence and abuse, of the CRPD. As stated by Flynn & Lawson (2013), the CRPD is a comprehensive and broad-based human rights convention that requires attention to the interrelations between the different articles of the Convention itself, as well as other human rights law. The analysis of the interrelations and 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 within their societies, therefore, is crucial in understanding gender-based violence against disabled women. In addition, as the human rights approach recognizes the importance of "embedding lived experience in rights based claims and in the development of social justice theories" (Degener, 2016, p. 6), exporting the lived experience of disabled women is also key in understanding violence, and empowering disabled women in claiming their rights to justice as human rights holders (Degener, 2016; Skarstad & Stein, 2018).

Violence and Access to Justice

International human rights bodies express significant concerns regarding the persistent and high levels of violence against women (Council of Europe, 2011; FRA, 2014; WHO, 2001). Of even graver concern is that international research shows that disabled women are at a higher risk than other women to experience violence (Hughes et al., 2012; Krnjacki, et al, 2016; UNFPA, 2018). Other studies have revealed that disabled women experience violence for longer durations than non-disabled women (Yoshida et al. 2009; Barrett et al. 2009), as well as a wider range of violence (Nixon 2009), and partners and/or caregivers are usually the perpetrators of violence in their homes (Heilporn et al. 2006; Brownridge 2006; Mays 2006; Hassouneh-Phillips and McNeff 2005; Yoshida et al. 2009; Martin et al. 2006). Most research on violence against disabled women has focused on the forms and frequencies of violence (Hughes et al, 2012; Krnjacki, et al, 2016; Corcoran and Smith 2016), how violence affects disabled women's mental and physical health (Barrett et al. 2009; Olszowski and Boaden 2010; Macdonald 2015; McClimens and Brewster 2017; Rowlands and Amy 2017; Haraldsdóttir 2017) and access to support services (Snæfríðar-Gunnarsdóttir and Traustadóttir, 2015; Sha, Tsitsou, and Woodin 2014; Woodin and Shah, 2015). However, limited research has focused on access to justice for disabled women who have been subject to violence. The majority of the research on access to justice has investigated the justice system in general, the physical accessibility of courts and justice buildings, litigation, and the participation of disabled people in different roles within the justice system e.g. being a witness and/ or a jury member (Ortoleva 2011; Ziv 2007; Mulcahy 2007; Kearney and Merrill 2000). When it comes to research on disabled women accessing justice to report and/ or prosecute violence, there is very little research conducted internationally. The lack of access to justice as well as the limited research focusing in this area may result from the fact that much of the violence disabled women experience is structural violence where it is difficult to point to a perpetrator.

Conclusion

This article has emphasised the complexity of violence and disability and highlighted the importance of understanding the cultural, social, historical, political, legal, and economic contexts in which gender-based violence against disabled women occurs. It has also outlined how the human rights approach to disability and violence, articulated in the CRPD, goes beyond social and cultural approaches by demanding full disability equality and the recognition of the discrimination resulting from the intersection of disability and gender. Ending the widespread violence against disabled women and ensuring that they have access to justice when subject to violence, calls for new research taking into account all the complex forms, contexts and approaches creating and legitimating this violence.

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3 The right to liberty and security of persons living with dementia in residential aged care settings in Ireland

Ainsley K McLean

Abstract

The growing practice of institutional care among older persons living with dementia is particularly evident as the ageing population expands. In light of 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 the most fundamental of all rights; inherent dignity, individual autonomy as well as the right to liberty and freedom of movement. In its novelty and interest to a global readership, this chapter will investigate the scope of the right to liberty and security of persons concerning persons living with dementia – who may find themselves in receipt of institutional aged care without their consent, based on perceived or actual disability. Although this is a timely and critical human rights issue, it is not absolute. In the specific context of Ireland, two legal routes can lawfully trigger a deprivation of liberty; the Mental Health Act, 2001 and the Ward of the Court's system. This chapter will draw from the synergies of disability studies and international human rights law; specifically, the advent of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) - with particular focus on Article 14 (the right to liberty and security of persons with disabilities).

Introduction

The right to liberty and freedom of movement is a fundamental human right; however, it is not absolute, meaning that persons with disabilities are often subject to State practices that allow for the deprivation of liberty on the "grounds of actual or perceived disability." (CRPD, 2007, Article 1). Therefore, this chapter endeavours to investigate disability-specific deprivation of liberty in the context of persons living with dementia who may find themselves in receipt of residential aged care without their consent, as applied to the Irish context. In order to address this salient issue, this chapter will seek to explore the apparent tension between guardianship measures in domestic law - which legally trigger a deprivation of liberty in certain circumstances; the Mental Health Act, 2001 and the Wards of Courts system. Moreover, Article 14 of the UN Convention on the Rights of Persons with Disabilities - which states that "the existence of a disability shall in no case justify a deprivation of liberty.' (CRPD, 2007, Art 14).

Three key sections will frame this chapter; First, a contextual background will provide insight into the proliferation of residential, institutional care, as it applies to persons living with dementia in the Irish context. Secondly, this section will establish persons living with dementia as a meaningful rights-based holder under the auspices of the CRPD -who are specifically, intended as beneficiaries of the Right to Liberty and Security of Persons – pursuant to Article 14 of the CRPD. Thirdly, it will investigate whether guardianship measures can legally trigger deprivation of liberty as it applies to persons living with dementia in the Irish context. Therefore, two legal routes that currently operate in Irish domestic law: the Mental Health Act, 2001 and the Wards of Courts system.

Background

The proliferation of institutional care can affect the most fundamental of all rights; inherent dignity, individual autonomy as well as the right to liberty and freedom of movement. In this section, it will consider the proliferation of residential institutions as it applies to persons living with dementia to the Irish context. First, this section will contextualise dementia through a disability and human rights framework.

In contrast, from a medical paradigm, dementia is a "syndrome or set of neurological symptoms that denotes a cognitive, sensory and functional decline" (Kenigsbery et al., 2015). Moreover, 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." (World Health Organization, 2019). In divergence, and shift of tone, Alzheimer Europe (2017) 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". (Gove et al., 2017).

Dementia is a significant cause of disability among people over 65 years of age, and the prevalence is rising (Alzheimer's Association 2016). 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 47.5 million persons living with dementia, with a further 7.7 million new cases diagnosed every year. (Alzheimer's Disease International and WHO, 2012). The European Union (EU) is facing significant demographic changes, with population ageing being a common challenge for the Member States in the medium to longer-term perspective. (Spasova et al. 2018). Within the EU, public expenditure on long term care projects an increase from 1.6% to 23.7% of GDP between 2016 and 2070. (European Commission, 2018). Dementia is not exclusive to old age; however, it does exponentially increase with age with a 'doubling for every 6.3-year increase age'. (Prince et al. 2015). Prevalence rates for the Irish population also ' demonstrate a sharp rise in the prevalence of dementia with age.' (O'Shea, 2007).

Across the Irish landscape, there is an abundance of large segregated residential institutions specifically designed for persons living with dementia. According to O'Shea et al. (2019), 55,266 persons are living with dementia in Ireland. While the vast majority choose to reside in their own homes in the community, "19, 500 persons receive institutional care." O'Shea et al., 2019). Although, it is worth noting at this point that Ireland declares a much lower level of institutional care among persons living with dementia than most other OECD countries (O'Shea et al. 2019). Further scrutiny is warranted to investigate what the actual conditions regarding informed consent are for persons living with dementia in these institutional settings as to date it is not entirely clear whether informed consent had occurred, before or during admission. Currently, are no epidemiological studies available in the context of Ireland to determine this. (O'Shea, 2019).

The Right to Liberty for Persons Living with Dementia in Residential Aged Care Settings

In this section, it will first establish persons living with dementia as a meaningful rights-based holder under the auspices of the CRPD. Secondly, as intended beneficiaries of the Convention, persons living with dementia have the right not to be unlawfully or arbitrarily deprived of their liberty on the grounds of perceived or actual disability (CRPD, 2007, Article

1). Thirdly, it will examine Article 14 of the CPRD in the context of care, provided for in locked facilities, where freedom of movement is severely restricted.

First, The CRPD gives, voice, visibility and legitimacy to all persons with disabilities, including persons living with dementia. The CRPD facilitates "respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons." (CRPD, 2007, Preamble). This international human rights approach "reflects a paradigm shift from a medical approach to a rights-based approach, where equality is the central frame of international human rights law." (Mental Health Europe, 2020).

There are several Articles of the Convention, relevant to persons with dementia; Article 12 – equality before the law and Article 19 – independent living and community inclusion to highlight a few. Arguably, one of the most "precious rights" of the Convention is Article 14 – the right to liberty and security of persons. (Committee on the Rights of Persons with Disabilities, 2015, para 3).

The adoption of the CRPD by the UN General Assembly on the 13 December 2006, entered into force on 3 May 2008. This human rights treaty signalled a "new era for people with disabilities" (Lawson,2007). Although the Convention does not define disability, in an interpretative sense, it considers persons with disabilities to include those with "long-term physical, mental, intellectual or sensory impairments, in which interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." (CRPD, 2007, Art 1). Furthermore, the CPRD "ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, by promoting the respect for their inherent dignity." (CRPD, 2007, Article 1).

Secondly, there is little doubt that the cognitive and physical impairments caused by dementia are fully recognised as a disability and therefore, explicitly recognised as intended beneficiaries of the Convention (Gove et al. 2017). In essence, the CRPD reaffirms the rights of persons with dementia to "determine their level of care and engagement in society, to which active participation and inclusion can be fully recognised". (Brooker, 2007).

The Irish government ratified the CRPD, March 2018, which affords all persons with disabilities, including dementia to be meaningful human rights holders under the auspices of the CRPD. From a human rights perspective, this is a significant development towards the right to facilitates one's own decision-making ability, particularly in light to care and place of residence. As articulated by Mental Health Europe (2020), such recognition ensures the preservation of autonomy and inclusion for persons with disabilities as well as equal dignity. (Mental Health Europe, 2020).

Thirdly, Article 14(1)(a) of the CPRD, has been identified as one of the 'most precious rights to which everyone is entitled' particularly for people with cognitive disabilities, to assert their right to liberty and freedom of movement. (Committee on the Rights of Persons with Disabilities, para 3). Furthermore. "State Parties are required to ensure that people with disabilities, are on an equal basis with others, enjoy the right to liberty and security of persons, and are not deprived on their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability of liberty.' (CPRD, 2007, Article 14). Nonetheless, despite such promise, this right is not absolute. The Special Rapporteur on the Rights of Persons with Disabilities has identified what constitutes a deprivation in liberty in the context of residential institutions as a "restriction in space or place of institution setting, not free to leave, and without free and informed consent." (2019 para 40).

Furthermore, as articulated by Pyaneandee, through Steele et al. (2019) "Confining people living with dementia within residential aged care facilities through locked doors and gates can be framed as a violation of the right to liberty and security of the persons, provided for by Article 14(1)(a) of the CRPD.

Deprivation of Liberty in the Context of Irish Guardianship Legislation

Although as argued in the previous section, the CRPD prohibits the deprivation of liberty on the grounds of perceived or actual disability (CRPD, 2007, Art 1). This section, therefore, highlights the context in which guardianship legislation can lawfully trigger deprivation of liberty as it applies to persons living with dementia to the Irish context. This section will specifically focus on two legal routes: First, The Mental Health Act, 2001 and Secondly, the Wards of Courts system.

Persons living with dementia are "subject to unique forms of deprivation of liberty, often justified by reference to the need to protect their right to life, right to health, and to protect the human rights of others." (Flynn, 2016). In the specific context of a person's living with 'severe dementia.' The Mental Health Act, 2001, can lawfully deprive a person of their liberty - through the legal definition of "mental disorder," which states, "mental illness, severe dementia or significant intellectual disability where (a) because of illness, disability or dementia, there is a serious likelihood of the person concerned causing immediate and serious harm to himself or herself or other persons, or (b) because of the severity of the illness, disability or dementia, the judgment of the person concerned is so impaired that failure to admit the person to an approved centre would be likely to lead to a serious deterioration in his or her condition or would prevent the administration of an appropriate treatment that could be given only by such admission." (Mental Health Act, 2001, s 3(a)(b)).

Nonetheless, it is critical to consider the context in which deprivation can legally occur under the provision of the Act. In accordance, with Section 3(b) of the Mental Health Act, 2001. Lawful deprivation can only occur in approved centres, like psychiatric hospitals or institutions. This is not indicative of private residential aged care facilities, to which deprivation frequently occurs, usually through informal avenues; reliance on "next of kin" and "Enduring Power of Attorney (EPOA) decision-making processes. Therefore, the fundamental questions remain – under what legal circumstances, can a person living with dementia, find themselves in receipt of non-consensual residential aged care as it applies to the Irish context. In order to further develop this argument, interpretation can focus on the Wards of the Courts system.

The Ward of Courts system (an archaic form of adult guardianship) operates on the premise of "mental incapacity" (Browne & Murphy, 2020). Of particular importance, is situations, where persons living with dementia are presumed to lack mental capacity, by default of diagnosis, according to Browne & Murphy (2019). The Ward of the Court systems relies on satisfying the court; "by deeming a person as incapable, of terms of managing his or her affairs due to a lack of mental capacity". (Browne & Murphy, 2020). In essence, this renders a person "incapable of exercising their legal rights" (Wright, 2019). Consequently, this "perpetuates a culture of discrimination and exclusion, by limiting every aspect of an individual's life, such as the right to choose, where and whom to reside. (Mental Health Europe 2020).

Conclusion

This chapter has endeavoured to reframe dementia through a disability and human rights narrative, with the overall intent to establish persons living with dementia as meaningful rights-based holders under the auspices of the CRPD. Particular focus is right to Liberty and Security of Persons - pursuant to Article 14 of the CRPD. In an attempt to address the centrality of this chapter's research question, a brief investigation into the proliferation of institutional care as it applies to the Irish context was discussed in relation to what constitutes a deprivation in liberty, in the specific context of residential aged care settings. Further development to this chapter’s argument then considered: two legal routes that currently operate in domestic Irish law; the Mental Health Act, 2001 and the Wards of the court's system - which legally permit deprivation of liberty in specific situations. This chapter is no means exhaustive. The primary focus of this chapter was to generate further discussion and debate about what is significant, but the often invisible, issue for many older persons living with dementia, particularly in the specific care of residential aged care settings. This chapter has endeavoured to address a glaringly absent, yet important voice - persons living with dementia who reside in these institutional care settings. It is, therefore, in this vein, to which this chapter seeks to address this gap in policy and practice.

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4 Strained advocacy: how reproductive rights has caused discord within the feminist and disability rights movements

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> *"The better we understand how identities and power work together from one context to another, the less likely our movements for change are to fracture."* (Crenshaw, 2015)

Abstract

This chapter addresses how historically entrenched contentions between the disability rights and feminist movements have impacted not only advocacy, but policy and practices around fetal impairment and reproductive rights at the global level and within national contexts. Linking foundational contributions from disabled activists and feminists in disability studies to recent global level discussions on bioethical implications of reproductive technology and selective prenatal screening practices, the chapter aims to highlight the most sustained points of contention between the feminist and disability movements. Drawing on recent dialogues within UN human rights monitoring bodies on issues of fetal impairment, it is highlighted that both the feminist and disability rights communities are attempting to move beyond divisive and reductive advocacy positions such as claiming that individual choice should be the only response or selective abortion should never take place. Despite such moves, examples of legislative shifts at the national level in Iceland and Ireland show that tensions between the feminist and disability movements have contributed to continuing disability discrimination within reproductive health policy and practices. The chapter ultimately contends that there is an immediate need to foster collaboration and joint advocacy between movements at all levels in order to ensure policy and practice around reproductive technology and issues of fetal impairment truly reflect the values of both communities.

Introduction

The disability rights and feminist movements have both centered their advocacy on the universal human rights principles of bodily autonomy, self-determination, equality, and choice (Anderson, 2017). However, topics of reproductive technology and its increasing ability to detect fetal impairment have been a point of significant and growing tension between these communities. While this tension between the movements has been predominantly documented and addressed by disabled feminists, the rapid advancement of reproductive technology and its diagnostic abilities has increasingly required the engagement of the mainstream feminist movement on issues of disability. The push for reproductive justice[1] and the general demand for a more intersectional feminist movement led by women of color, has seen disability increasingly included within mainstream advocacy agendas (Sister Song, 2020). However, the historic marginalization of disability rights and the experiences of disabled people in the feminist movement have acutely impacted not only advocacy, but policy and practices around reproductive rights and fetal impairment at the global and national levels. This chapter will trace how the limited and precarious space disabled people hold within the mainstream feminist movement, greatly informs the environment in which disability activists and reproductive rights activists are holding conversations regarding advancing reproductive technology, fetal impairment and the bioethical implications involved in such issues. It will further draw on recent global level dialogues, as well as national level policies in Iceland and Ireland to illustrate how the concerns raised from the disability community continue to be largely marginalized in feminist advocacy spaces and how this discord is reflected in the newly codified national policies and practices.

Historical Discord

Since the introduction of prenatal diagnostic screening, disabled feminists have raised concerns regarding the increasing breadth of choices and consequences prospective parents must negotiate, and how those choices impact entire communities and populations (Asch, 1999, 2005; Fine, 1988; Finger, 1983a, 1983b, 1985; Parens & Asch, 1999, 2000; Saxton, 1988; Wasserman, 2006; Waxman, 1994; Wendell, 1989). While uncompromisingly upholding a woman's right to abortion and autonomy of choice, disabled feminists have also raised difficult questions around what happens when that choice extends from choosing *if* you want to have a child to choosing *what kind* of child (Asch, 1999, 2005; Saxton, 1988; Shakespeare, 1998; Wasserman, 2006). With the rapid advancement of reproductive technology and growing implications for policy and practice, there are increasingly more actors who are engaging in discussions around the bioethical implications of reproductive technology and fetal impairment, including bioethicists, medical practitioners, medical anthropologists, and social scientists amongst others (Kuhse, 2009; Newell, 2006; Ouellette, 2011). However, for those within the feminist and the disability movement the link between the body and techno-science is acutely personal. As such, the focus will remain for this short chapter on the relationship between the disability rights community and the mainstream feminist movement on these issues.

D.A. Caeton in their piece "Choice of a Lifetime: Disability, Feminism, and Reproductive Rights" analyses the relationship between feminism and disability studies on issues of reproductive rights and remarks, "[f]eminists might be thought of as the wise older sisters of

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[1] Drawn from the organization Sister Song, Reproductive Justice is defined as "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities" (Sister Song, 2020)

disability studies scholars; but, as anyone with siblings knows, life offers occasions where we find ourselves in profound disagreement with those whom we are inseparably related." (Caeton, 2011, p. 4). Renown feminist disability studies scholar Rosemarie Garland Thomson echoes this sentiment saying that feminism and disability studies, while orbiting common issues, often work at cross-purposes. As Garland-Thompson further relays, feminism often ignores or siloes the contributions of disability studies, and disability studies scholars equally lack a general understanding of feminist theory and its institutional frameworks (Garland Thomson, 2013). Notwithstanding, the work of many feminist disability scholars has made significant headway in creating greater collaboration and providing critical tools to foster dialogue between feminist frameworks and disability studies, including the development of multidisciplinary theories as what Garland Thomson has termed "Feminist Disability Theory" (Garland Thomson, 2013). Using her understanding of feminist theory as a way of "investigating how culture saturates the particularities of bodies with meanings and probes the consequences of those meanings" we can see that intertwining feminist theory and disability studies provides us with a rich framework to understand the vast complexities of disabled women's experiences, particularly around reproductive rights (Garland Thomson, 2013, p. 335).

It is critical, however, to frame the current discussion regarding reproductive technology and fetal impairment within the context of the historical advocacy relationship between the mainstream feminist and disability movements.[2] Issues of reproductive rights have remained one of the most sustained points of contention, and mainstream feminism has long been criticized for dismissing, and at points, actively excluding disabled women.[3] The mainstream feminist movement has historically perceived the issues of disabled women as either too complex, or unrelated to what 'women' as a homogenous group experience, and that this specificity could 'muddle' collective advocacy. This was particularly apparent in feminist discussions around reproductive rights, where there was little acknowledgement that different women have different priorities within reproductive rights (McLaughlin, 2003). Feminists in disability studies note that disabled women's priorities around the right to motherhood and issues around involuntary sterilization were dismissed within non-disabled feminist's advocacy, prioritizing a 'united front' advocating for the right to choose not be mothers (Björnsdóttir, Stefánsdóttir, & Stefánsdóttir, 2017; Traustadóttir, 2004a). In addition much of the early advocacy and campaigns for abortion rights utilized the fear of congenital impairments, in tandem with issues of rape, to garner widespread support for a woman's right to choose (McLaughlin, 2003). The bodies of disabled women, which were perceived as 'weak' or 'dependent' were also seen to disrupt the early mainstream feminist push to present women as independent, strong and autonomous (Thomas, 2006). These perceptions of disabled bodies have infiltrated the continuing narrative that positions disabled people as a

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[2] The term mainstream feminist movement will be used to discuss dominant feminist advocacy positions, acknowledging that there are as Garland Thomson has said many 'feminisms'. (Garland-Thomson, 2017)

[3] Within the context of advocacy, the term disabled women is inclusive of disabled trans women and those that identify as gender non-binary, of whom have played a critical role in the feminist disability movement.

‘burden’ or target of care within central feminist advocacy points of unpaid care work (Traustadóttir, 2004a). This can be currently seen in the context of feminist advocacy during the 2020 COVID -19 pandemic, where mainstream feminist institutions like UN Women frame the discussion of non-disabled women’s increased care burden for disabled family members, the elderly and for children, excluding recognition that disabled women too are primary carers and heads of households (Traustadóttir, 2004b; UN Women, 2020). With the birth of the Reproductive Justice movement which aims to address the “intersections of multiple oppressions and is inherently connected to the struggle for social justice and human rights”, disability activists have found a space amongst other communities, including indigenous, trans, queer, migrant, incarcerated, and people of color, that have felt ostracized from the mainstream feminist movement (Sister Song, 2020). With the collective advocacy of such communities around Reproductive Justice, the disability community has been able to utilize a more holistic framework that advocates for their particular, and universal, sexual and reproductive health and rights. With regard to Reproductive Justice and disability, activist Mia Mingus highlights that “[d]isabled women and girl’s bodies have long been invaded and seen as the property of the medical industry, doctors, the state, family members, and care givers” and through the Reproductive Justice framework can increasingly advocate against the largely ableist mainstream feminist movement (Mingus, 2007, p. 24).

Global Level discourse

The heightened tension between the movements on the issues of reproductive technology and fetal impairment, has most recently been highlighted at the global level. The UN Special Rapporteur on the Rights of Persons with Disabilities recently released a report on “Bioethics and Disability” (2020), where, in echoing earlier disability activists, her office calls for health policies, abortion laws and the larger reproductive health community to evaluate deep rooted and perpetuating ableism whilst maintaining the autonomy and right for every woman to choose (UN Human Rights Council, 2020). This report in part responds to the increasing tension building within and between United Nations human rights monitoring bodies, particularly the Committee on the Convention to Eliminate Discrimination Against Women (CEDAW) and the Committee on the Convention on the Rights of Persons with Disabilities (CRPD). Both Committees have come into conflict over the issue of fetal impairment, notably in the country reviews of Spain and Hungary (Petersen, 2015). For both country reviews, the CRPD Committee’s comments to the Hungarian and Spanish governments cited discrimination on the grounds of disability (Article 5 of the CRPD) with regard to their laws allowing abortions or extended time for abortions based on fetal impairment (Petersen, 2015). The CRPD Committee’s recommendations raised concern amongst reproductive rights advocates who feared it would encourage Spain and Hungry to restrict abortion rights. The CRPD Committees comments were further criticized by both scholars and activists (on both sides) as being far too simplistic in addressing the issues of reproductive rights and fetal impairment. These conversations coincided with the 2018 campaign and election of Ana Peláez, the first disabled woman to be elected to the Committee on the Elimination of Discrimination against Women (CEDAW) in its then 37 year history (European Disability Forum, 2018). Peláez, who was nominated by her home country of Spain, came under scrutiny from the feminist community when calling for a more nuanced conversation regarding Spain’s legislation to extend the abortion window based on fetal impairment diagnosis. The disagreement between human rights monitoring committees, the election of a first disabled women to CEDAW, and the Special Rapporteurs report addressing ableism and bioethics, all reflect that there is a continuing, albeit shifting, homogenous approach to reproductive health and rights activism. As a result, these complex ethical discussions have led disabled feminists to remain feeling consistently excluded from mainstream sexual and reproductive rights advocacy and the feminist community at large.

National level shifts: Iceland and Ireland

Turning to examples at the national level, both Ireland and Iceland have undergone significant changes in their reproductive health legislation and policies since 2018. While very different in tenor, these legislative changes have been instigated by ongoing cultural and socio-political shifts in attitudes towards reproductive health and rights at the national level. For both countries, national conversations and debates around these legislative changes highlighted ongoing ethical discussions on prenatal testing and fetal impairment. Icelanders in particular have grown accustomed to receiving high quality reproductive health care based on the newest advances in technology, being one of the first countries in Scandinavia to encourage systematic prenatal screening (Gottfredsdottir & Bjornsdottir, 2010; Gottfredsdottir, Sandall, & Bjornsdottir, 2009; Knudsen et al., 2003). However, the 2019 Pregnancy Interruption Act ("Lög um þungunarrof,") replaced the 1975 Act on Counselling and Education Regarding Sex and Childbirth and on Abortion and Sterilization Procedures ("Lög um ráðgjöf og fræðslu varðandi kynlíf og barneignir,") and reignited national debates surrounding fetal impairment and the widespread use of prenatal testing, including the potential use of non-invasive prenatal testing (NIPT). With international media, and national advocacy groups raising alarm at the decline in the number of births of children with Down syndrome, there has been an increased intensity in the national dialogue around screening for and aborting fetuses with impairments (Quinones & Lajka, 2017; Will, 2018). Icelanders are increasingly grappling with when selective reproduction becomes a collective responsibility rather than an individual moral choice (Gottfreethsdottir & Arnason, 2011; Heinsen, 2018).

Several studies have documented the rapidly increased usage of prenatal screening in Iceland since the introduction of nuchal translucency (NT) screening in 1999, to the current discussion of increasing the use of non-invasive prenatal testing (NIPT) (Gottfredsdottir, 2009; Gottfredsdottir & Bjornsdottir, 2010; Gottfredsdottir et al., 2009; Hill et al., 2016). NIPT has increasingly become a subject of reproductive health discussions in Europe due to its minimally invasive procedure, increased accuracy for detecting anomalies, and almost eradicating the already low potentiality[4] for inducing miscarriages. These factors have predicted the push for even further use and routinization of prenatal testing. This has simultaneously heightened the concern over how prospective parents are making decisions regarding prenatal texting and the major factors involved in influencing their choices, (Slgurðardóttir, January 23, 2019) and the entrenchment of historical divides between the feminist and disability communities in Iceland (Traustadóttir, 2004b). Disability rights groups

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[4] Prenatal testing procedures, used to detect Downs syndrome, that have been used prior to NIPT including amniocentesis and chorionic villus sampling have a miscarriage rate of 1% and 1.5% respectively (Ogilvie & Akolekar, 2014).

and those concerned over selective prenatal testing have increasingly drawn parallels with Iceland's neighbor Denmark (Slgurðardóttir, January 23, 2019). In a 2014 ethnographic study regarding selective prenatal testing and abortion in Denmark, it was cited that 99% of prospective parents who receive a positive diagnosis for Down syndrome choose to terminate (Heinsen, 2018). Ethnographers in Denmark have recently questioned how the routinization of prenatal screening, where over 90% of Danish women nationally opt for prenatal screening[5] has contributed to the conventional response of aborting the fetus with the fetal anomaly (Heinsen, 2018). While Iceland has key demographic differences to Denmark, notably a much smaller population, disability rights advocates in Iceland have highlighted the similar cultural push in reproductive health services to routinise prenatal testing (Öryrkjabandalag Íslands, 2017). Considering the new legislation and the increasing advocacy amongst the medical community to mainstream reproductive technologies such as NIPT in Iceland, there remains limited information regarding how prospective parents are supported in making decisions and potential ways forward to ensure prospective parents feel prepared and secure in their choices around prenatal testing and fetal impairment.

Unlike Iceland, Ireland has an intensely conservative history regarding reproductive health and rights, and the recent passing of the Health (Regulation of Termination of Pregnancy) Bill (2018) legalizing abortion up to 12 weeks has been a significant cultural and political shift for Ireland ("Health (Regulation of Termination of Pregnancy) Bill," 2018; Irish Family Planning Association, 2019). A significant factor in this shift in reproductive health legislation were two high profile cases where two pregnant women, Amanda Mellet (Mellet v. Ireland, 2016) and Siobhán Whelan (Whelan v. Ireland, 2017) received fatal fetal diagnoses and were unable to receive abortions. As Erdman (2019) highlights, both of these cases claimed that Ireland's prohibition and criminalization of abortion had violated the International Covenant on Civil and Political Rights under the right to freedom from cruel, inhuman or degrading treatment (Article 7). Many disability rights activists and organizations advocated for the passing of the Health Bill 2018. However, both the high profile cases on fatal fetal impairment and the new law allowing the termination of a fetus based on fatal fetal diagnosis, has increased concern over unclear healthcare guidelines for practitioners on prenatal and genetic counselling and lack of guidance for prospective parents (Abortion Rights Campaign (ARC) & Disabled Women Ireland (DWI), 2019). Further, recent studies have revealed concerns that currently medical practitioners in Ireland are operating not only without a clear national policy on prenatal screening or national ultrasound guidelines on best practice, but also without universal access to ultrasound and anomaly scans (Donnelly & Murray, 2020; O'Connor, O'Doherty, O'Mahony, & Spain, 2019). The new policy and practice regarding abortion and a relatively new culture around prenatal testing has created a significant gap in information and knowledge about the factors that

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[5] Laura Louise Heinsen (2018, p. 71) cites from a 2008 and 2010 study (Ekelund et al. 2008; Schwennesen 2010: 13) that 90% of Danish women nationally and 98% in the Copenhagen area chose routine prenatal testing.

could influence the decisions of parents and professionals in antenatal care and potential diagnosis of impairment.

Although current policies, practices, knowledge and experiences are at very different stages in Iceland and Ireland, both countries face new realities that call for more information and knowledge regarding medical and ethical practices in prenatal testing, the experiences of individuals who are subject to the testing, and the views of advocates and policy makers. The historical tensions between the feminist and disability rights movements are critical to understanding how within a national context reproductive health policy and practice are formed, and particularly, who they are inclusive of.

Conclusion: Towards a collective advocacy

In collecting the rich contributions of disabled feminists on issues of reproductive rights and intersectional feminism from the last four decades, it is disheartening to see that the concerns of disabled feminists in the early 1980s remain as critical and unaddressed for disabled people today. While there have been great inroads to create and advocate for a more intersectional feminist agenda, issues around reproductive technology and its growing implications for selective screening have increasingly divided the feminist and disability rights community. As seen within global level dialogues and within legislative shifts at the national level, policy and practices are being shaped as quickly as the advancement of reproductive technology. For many within the disability community these policies and practices reflect the deep rooted ableism that has marginalized their engagement in the feminist movement. In questioning how to take a more nuanced and intersectional approach to reproductive rights and choice, D.A. Caeton reflects that “disability as physical and cognitive alterity” should be “understood as an alternative modality of being, one that is no less, nor no more, despicable than any other category of being” (Caeton, 2011, p. 22) It is arguably from this point where we must foster collaboration and joint advocacy, to influence policy and practice around reproductive technology and issues of fetal impairment which truly reflect the values of both communities.

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5 Institutional living, institutional dying? The intersecting goals of palliative care and the disability rights movement

Marissa Diaz

Abstract

Palliative care is a health approach that is implemented all over the world in order to improve the quality of lives of those faced with life-threatening illness. However, there are criticisms that the medical community cannot both deliver palliative care and maintain the ideological origins it was based upon. Palliative care aims to be more than the alleviation of physical symptoms, instead aiming to improve overall quality of life in the face of impending death and tending to non-physical pain as well. However, since physical symptoms relief is usually delivered within institutions such as hospices, this arguably presents a conundrum that contradicts that ideological origins of palliative care, which focus on the palliative care service user's needs and desires, which may include dying at home. This chapter aims to illustrate that there are intersections between the interests of palliative care and the disability rights movement, using the issue of institutional living as a case in point. It begins by briefly describing the roots of palliative care and its transformation into a health approach, focusing on its goal to improve quality of life in the face of death, essentially aiming for a good quality of life until one's "good death". It then explores the issue of the "good death" in palliative care and how the setting of one's dying plays into this issue. This chapter then introduces the issues of institutional living within the context of the disability rights movement and problematizes the delivery of palliative care, both in institutions and at home. It concludes that more research on the delivery of palliative care at home for persons with disabilities is necessary and more collaboration may prove fruitful.

Introduction

Diseases and injuries that compromise our health and well-being, once thought unavoidable, are now either curable or manageable. In healthcare, medical approaches denote a variety of ways medicine evaluates and treats said diseases and injuries [1], and over the past few centuries we have discovered new approaches through rapidly improving our understanding of the human body and its health. From the discovery of penicillin to the identification of stem cells, we have discovered treatments for what harms our health and techniques to manage or mitigate the damage that diseases and injuries cause. Yet, there is one ubiquitous health problem that we all face that no one can conquer: death. In part due to our incredible medical advances, healthcare professionals may refuse to accept the fact that sometimes there is nothing we can do to solve health problems [2] [3]. The blunt fact is that, at some point, curative healthcare can offer no more and death is unavoidable. Yet, that does not mean that healthcare professionals have nothing to offer those facing death: they can offer services that improve quality of life in the face of chronic health problems that cannot be cured.

Enter palliative care. The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" [4]. Unlike other healthcare approaches that focus on cure or rehabilitation to extend life and enhance functioning [5], palliative care aims to improve quality of life without intending to fix the underlying health problem. Since the dying process is often accompanied by pain, distress, and suffering, palliative care focuses on alleviating these problems as much as possible [6].

Death is obviously not a new phenomenon, but this current palliative approach to the dying is relatively new. Palliative care arose from the modern hospice movement in the 1960's, which, in turn, arose from a perceived neglect of the dying, specifically those afflicted with cancer. Palliative care has since developed into a health approach implemented around the world, no longer limited to the domain of oncology and often delivered in combination with curative treatment [7]. This transition from social movement to health approach has not been a smooth one. There have been concerns that the medical community cannot both deliver palliative care and maintain the ideological origins it was based upon; that is, a belief that care of the entire person is essential, focusing on physical, spiritual, and psychosocial sources of pain, summarized under the umbrella phrase "total pain" [8]. Beverly McNamara is particularly critical of the current state of palliative care, opining that a "good enough death" is what is aimed for, and, as a result, physical symptoms are being prioritized once again in a more medicalized version of the vision behind the modern hospice movement [9]. On a similar note, Stefan Timmermans believes that since that palliative care has been integrated into medicine, it has become less "radical" than it was before, with the medical community now having full cultural control of brokering "culturally-appropriate" deaths within hospice and other settings. [10]. Julia Lawton argues that hospices have (ironically) become the "death houses" that the modern hospice movement wanted to avoid, where those with unmanageable or unpleasant symptoms are sequestered away [11].

Along with the modern hospice movement that preceded palliative care as a health approach, another social movement that began challenging the medical model during the 20th century is the disability rights movement. The medical model views both disability and illness as a failure and have historically segregated those in less-than-perfect health away from others. Whereas the disability rights movement fights against ableist stigma and proclaims "nothing about us without us", palliative care aims to enable palliative care service users to "live until they die"; both aim to challenge normative viewpoints about the type of life society views as worthwhile. While both palliative care and the disability rights movement have a similar overarching regard for life, the disability rights movement does not reside within healthcare, whereas the modern hospice movement was born in healthcare and palliative care is still firmly centered there. In exploring these intersections and complications, this chapter aims to call for future collaboration.

This chapter aims to explore the intersections between the interests of palliative care (which originated in the modern hospice movement) and the disability rights movement, using the issue of institutional living as a case in point. In briefly laying out some of the criticisms which arose from palliative care's transition from social movement to health approach, this chapter aims to illustrate the conflicting goals of the modern hospice movement with the practical complexities of delivering physical pain relief in palliative care. Moving forward, this chapter then explores the idea of the "good death" and where palliative care can be delivered. For the purposes of this paper, "place of death" will be the phrase utilized to reflect the differentiation between "place of care", seeing as someone in palliative care can be receiving treatment for months [12]. When combined with the issue of institutional living, the issue of palliative care services being delivered in institutions is problematized through the lens of disability rights. This chapter seeks to be a jump-off point for academics by first laying out these intersections and making recommendations for collaborations that can be explored with future research.

Brief history of palliative care: from social movement to health approach

This section aims to provide a brief history of palliative care, beginning from its roots as a social movement and then into its transformation into a health approach. It concludes with the exploration of the overall aim of palliative care, in which a focus on improving quality of life, which translates to a focus on having a "good death" in spite of one's symptoms.

While aspects of palliating the pain of the dying have occurred since early modern medical practice [13], our current understanding of palliative care derives from the modern hospice movement with its origins in the United Kingdom. Dame Cicely Saunders is the founder of the movement, which began after she was moved by her experiences with patients experiencing unrelenting pain during terminal cancer [11]. Cancer has been with us since time immemorial; in the 1700's remedies like henbane and mandrake root were utilized to fight the feared ongoing pain that comes with it [13]. Cancer has continued to confound us, and even after decades of research, we are unable to eliminate this disease and the pain it causes. Saunders saw the ravages of cancer during her experience as a volunteer nurse and determined that there was a great need for improved pain control [14]. After becoming a doctor, she studied pain management in the terminally ill and concluded that it was important to deliver pain medication on a regular basis as opposed for waiting for the pain to get bad [15]. However, she also recognized that it was important to tend to the non-physical suffering of the dying as well. Coining the term "total pain", Saunders argued that we should attempt to palliate the numerous sources of pain experienced during the dying process - physical, psychological, social, emotional, and spiritual [16]. She founded St Christopher’s Hospice in 1967 and similar hospices began to spring up in the United Kingdom not long afterwards [17]. Thanks to subsequent publications and the training offered at St. Christopher's, the concepts behind the modern hospice movement spread to North America. Dr. Balfour Mount, a Canadian physician, is credited with creating the phrase "palliative care" in the 1970's because of his discomfort with the use of the word "hospice" [18], hence the continued use of the phrase today.

Palliative care became more well-known in the decades that followed, largely due to its emergence as a medical intervention. Interestingly, both palliative care and public heath began to come about as medical interventions in the 1980's, with both approaches being framed as within the medical model but interdisciplinary at the same time [19]. Medical advancements within the field of oncology, where the modern hospice movement originated from, also contributed to a wider awareness of palliative care. An increased global awareness of unmitigated cancer pain led the WHO Cancer Unit to begin advocating for and researching pain relief in the early 1980's [20]. In 1990, the WHO defined palliative care for the first time and began to advocate for its implementation around the world [21]. Since then, palliative care has evolved and is being delivered earlier in the disease trajectory as opposed to waiting until death is imminent [22]. Recently, the WHO called for palliative care to be integrated into all levels of health services, specifically primary care, in order to improve access and increase patient well-being [23]. Originating as a movement to challenge both medical practice and the larder culture surrounding the dying, palliative care is both interdisciplinary and undoubtedly centered in healthcare, where the diagnosis is the impetus for further action and engagement.

The transition from social movement to our current understanding of palliative care as a health approach has not gone without controversy. Many have wondered if the medical community would be able to provide palliative care without losing sight of the holistic approach that Saunders championed [24], or if palliative care will evolve into another thing entirely as it continues to broaden within public health [25]. There is reason to critically analyze this transition, especially with palliative care's focus (and, as we have seen in the history, its *raison d'être*) on physical pain control. With the medical approach to symptom control, there is a view that the emphasis on physical symptoms causes the other aspects of palliative care to become less important in comparison [26]. The medical model also requires measureable outputs, and it is difficult to identify outcome measures appropriate for use during end of life [27]. Even though the WHO identifies the improvement of quality of life as one of palliative care's many aims, Fiona Randall and R.S. Downie argue that quality of life, measured quantitatively or qualitatively, should not be the aim of palliative care. They state that it is not possible to construct a scale that accurately reflects the everyday, multifaceted factors that contribute to quality of life, and that it is not appropriate for palliative care to focus on aspects outside of health, such as self-esteem and life satisfaction [28]. It is also impractical to try to measure the "quality" of a death, since it is impossible to appraise a patient's quality of life post-mortem, or to even quantify what a "good death" is without putting forth normative ideas about what exactly constitutes a "good death" in the first place.

Controversies regarding "the good death" (and if it can even be achieved) did not begin with this transition, but they have not been solved by palliative care, either. Although criticisms of how death is handled by health professionals continue to this day [10] [29], some opine that palliative care does not provide the perfect answer to the issues that Saunders identified, namely on how to achieve a "good death" without being treated as a lost cause. As explored in the next section, practical difficulties of dying further complicate the delivery of services.

"The good death": where we live until we die

When someone is identified as being in need of palliative care services, where do they go? Typical institutional settings include inpatient palliative care units, inpatient hospices, day cares, day hospices, and nursing homes [30]. Where one goes depends on a variety of factors, including what services the palliative care service user requires and the service model used where they live. However, the availability of these institutions also depends on financing; in some countries, palliative care is not always integrated into health systems, and it is paid for by public, private, and charitable sources [31]. This chapter describes institutional settings where palliative care is delivered and its benefits, while also highlighting the segregation of the dying person that arguably happens in said institutions.

The needs of palliative care service users are varied, but at end-of-life, increased support is usually required. Dying, is often a messy, unpleasant experience, both for the dying person and those who witness it. In the variety of institutional settings listed above, palliative care service users can be supported during this difficult time through a variety of interventions and treatments that aim to improve quality of life. Within these institutional settings, however, some have found that certain types of dying are more "good" than other types. Julia Lawton, following her ethnographic study of an English hospice, found that those that are dying "unbounded" deaths (those that do not align with cultural ideals, such as those that involve involuntary urination or defecation) are sequestered away from the main rooms of the hospice, away from other palliative care service users. [32]. Similar findings have been made in other studies. In an ethnographic investigation of a medical ward, Elisabeth Dahlborg-Lyckhage & Eva Lidén found that palliative care service users were usually placed with a handful of other service users unless they were in their "final phase", and then they were moved into their own rooms [33]. The irony of these studies is that Saunders herself wished for palliative care to be delivered in warm, inviting setting to contrast the medicalization of the dying process [12].

Arguably, the sequestering of those dying unpleasant deaths is related to a variety of issues. The privacy of the palliative care service user could be a concern, and there may be a wish not to traumatize other palliative care service users as well [12]. In addition, hygiene management (when it comes to urination or defecation) may prove troublesome for service providers. Workload and too little staff can be another issue at play. Burnout is common issue in palliative care and healthcare in general [34]; if palliative care institutions are spread thin, then there are less people around to deal with those dying "unbounded" deaths. While the delivery of palliative care in institutions seems to replicate the "death houses" Saunders rallied against, it is important to note that dying is a complex time in one's life, and different people will have varied opinions on where they want to receive care.

It is important to acknowledge the cultural context of this issue. Lawton acknowledges that largely "Western" ideas of the self permeate discussions about the body and its death [32]. Considering that the modern hospice movement started in the UK, it is impossible to divorce palliative care's ideals from the cultural context in which those ideals were sculpted. Zaman et. all call for a "suite of solutions" as opposed to a one-size-fits-all approach to palliative care interventions in order to reflect the variety of historic and cultural factors that come into play when trying to achieve "the good death" [24]. Palliative care has a broad enough definition to be flexible, and the delivery of its services can look very different in different regions based on different needs, or even simply due to individual palliative care practitioners making changes and paying attention to individual's needs [35].

Institutional settings are not the only places that can deliver palliative care services. Palliative care aims to deliver care that improves quality of life, including home care. Many studies have found that people wish to be at home when they die, and this is treated like an absolute truth within some texts [36]. One could see how this would be true; instead of placed within the walls of a hospice or another institution, a palliative care service user can spend the end of their lives in a familiar setting, surrounded by loved ones (assuming they have them). However, there can be complications that make home care impossible. In addition, not everyone wants to receive palliative care at home. The next section aims to explore the intersections and complications between the goals of palliative care and the disability rights movement and problematize practical issues concerning where palliative care service users wish to receive services.

Parallels with the disability rights movement: institutional living and palliative care services at home

This section aims to briefly explore the issue of institutional living, calling attention to the intersections between the disability rights movement and palliative care with regards to community care. This section concludes that there are areas in which palliative care practitioners and disability rights activists, scholars, and services can work in tandem in organizing palliate care delivery models that respond to the wishes of persons with disabilities, both within and outside of institutions.

First, what is an institution? According to the European Expert Group (EEG) on the Transition from Institutional to Community-based Care, an institution denotes any residential care where:

1) residents are isolated from the broader community and/or compelled to live together;
2) residents do not have sufficient control over their lives and over decisions which affect them; and
3) the requirements of the organization itself tend to take precedence over the residents' individualized needs. [37]

Institutional living is a disability rights issue, where it is contrasted with independent living and community living. According to the European Disability Forum, persons with disabilities are at a high risk of being put in institutions, and this risk in based in a history of segregating this population away from the community [38]. As illustrated in the previous section, people who receive palliative care services often go to institutions such as hospices, and this largely depends on their need and the availability of services. Lawton, however, contends that, during her fieldwork, she observed that people were placed in hospice not when their symptoms became unmanageable by the palliative care service user themselves, but when the symptoms of "unbounded" dying became too much for their carers, such as urination and defecation [32]. Upon first glance, this observation draws parallels to other reasons why persons with disabilities are institutionalized by their carers.

However, for some palliative care service users, institutions may provide a sense of security that one does not receive at home. MacArtney et. all found that [39] some people do not want to be at home when receiving palliative care services for a variety of reasons, including a wish to protect their loved ones from the physical and emotional challenges of delivering care outside of an institution [39]. The feasibility of home care is complex and depends on a variety of factors, but even when people wish to receive palliative care services in an institution, they are not always able to do so. This is why, according to the WHO, the accessibility of palliative care in the community is important and must be done through a variety of delivery models in order to improve the well-being of palliative care service users and improve access [23]. In order to response to a variety of palliative care needs, community care is required.

The definition of community care, according to the EEG on the Transition from Institutional to Community-based Care, is quite broad, including mainstream services from everywhere from housing to healthcare to education to leisure and beyond [37]. In addition, community care also encompasses specialized services "such as personal assistance for persons with disabilities, respite care and others" [37]. Using this definition as a jumping-off point, we can identify many opportunities for palliative care delivery outside of traditional institutions in collaboration with the community. Community palliative care programs are often run by non-profit organizations [3], allowing for collaboration with non-traditional services. Palliative care can utilize a variety of interdisciplinary methods to alleviate pain, such as massage or music therapy [40], which can be delivered outside of health services. Alongside health services, home health programs can be part of a community hospice program [3] and community specialists can work with hospital outpatient care services to allow a palliative care service user to receive care at home [41].

There are areas in which palliative care practitioners and disability rights activists, scholars, and services can work in tandem. Increased collaboration disability services and palliative care is required, for sometimes the needs of a person receiving disability services are lost in translation when they receive palliative care from another provider of care [42]. Those who provide disability services in communities are not confident that they can deliver palliative care nor are they aware that they can be trained in it [35]. For persons with disabilities who have received care in one setting for some time, the switch to palliative care services must not indicate the loss of the services they need in order to live their lives as they wish. It is also important to deliver palliative care to persons with disabilities without depriving them of their right to make choices about their lives, including at end of life. Communication is key for everyone at end of life, and persons with disabilities may feel that they are not listened to by others who think they know best [43]. The only way to ascertain someone's opinion on where they wish to die comes from open communication with the palliative care service user [39].

Beyond issues of institutional living, there are other practical reasons for more collaboration between palliative care and persons with disabilities. There are many accessibility issues when it comes to accessing palliative care services. Lack of access to sign language interpretation, ramps, and narrow hallways are just some of the physical barriers that can restrict access to palliative care services [44]. There are also attitudinal barriers that need to be addressed. It is also imperative that palliative care practitioners do not conflate the suffering that comes with dying with their assumptions about living with disability. Carol J. Gill expressly addresses this issue, calling for palliative care practitioners unlearn dangerous misconceptions about living with disability and not to view suffering as something that diminishes life's value [43]. Nina Streeck make a similar note regarding the "taboo" of suffering in palliative care, opinion that palliative care's goal to alleviate every facet of suffering (physical and otherwise) can have adverse effects on both patient and practitioner, who may attempt to avoid it at all costs and inadvertently promote assisted dying [45]. With an increasing number of persons with disabilities living longer, their needs will become more amplified and important to approach with a variety of different models of care; however, this will need to be done with sensitivity to the disabled experience, with palliative care practitioners learning about suffering within the context of disability and the potential to thrive outside of the medical model's expectations [43].

Conclusion

Palliative care is centered in healthcare, but due to the multifaceted nature of suffering that comes alongside dying, it requires outside engagement. If dying were simply a matter of pain control, then it would be relatively easy to deliver pain relief within institutions and leave it at that. However, people have a combination of needs at the end of their life. In order to respond to an aging population with varying demands, more heterogeneous models of palliative care are required [46]. Abel et. all argue that a solely clinical model is unable to meet the numerous needs that arise in palliative care, stating that between specialist palliative care, generalist palliative care, compassionate communities, and the civic approach (schools, churches, workplaces) to end-of-life care [41]. Cicely Saunders states that, in her native UK, the focus on palliative care being delivered in a physical building took away from the notion that it would be delivered at home, which missed the point that palliative care was based on "attitude and skills", independent of where it is delivered [11]. In promoting further collaboration with palliative care services, disability rights activists and scholars can investigate palliative care through academia and grassroots efforts in order to produce an evidence-base for future change. While there is relatively little research on the intersections of palliative care and disability studies, continued investigation can reveal the common interests in both fields.

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6 Training research skills as part of participatory research methods

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Abstract

There is a growing interest in participatory research methods and in including persons with disabilities in research. However, this does not come without challenges. Research methods can be disempowering and disabling. Persons with disabilities have accessed less education and experiences within academia, in contrast with the lengthy education most researchers have behind them. This means that embarking in a research experience as a co-researcher brings along difficulties and barriers which must be taken into account. Non-disabled researchers often take on the role of attending the methodological requirements of the project and making the decision making process accessible. This may undermine the participatory nature of the research and *de facto* translate into taking control over the research. It is difficult to participate without any prior knowledge on why and how research is done and power imbalances may arise. Past participatory research projects have explored the question of training as part of the team building and developing rapport between the non-disabled researcher(s) and the disabled researchers. Previous research projects also show that the techniques used during the trainings, e.g. visual support like drawings, also facilitated the involvement of researchers with disabilities. This chapter will explore the existing experiences and propose a training programme for persons with intellectual disabilities who have not engaged in research before.

Introduction

Participatory research (PR) has gained importance for pragmatic and equity reasons, particularly in health and development studies (Cornwall & Jewkes, 1995). Within disabilities studies, participatory research has been a demand from disabled researchers (Barnes, 2003) but also a concern of non-disabled researchers. Persons with intellectual disabilities are particularly hit by this exclusion within research (Goodley 1996; Mietola, Miettinen, and Vehmas 2017; Atkinson 1997).

This project will explore participatory research methods with persons with intellectual disabilities in Spain. As part of the project, the researcher will deliver training sessions prior to launching a participatory research proposal. This paper discusses the content of the training sessions and examines following questions:

1. What forms of participatory research with persons with intellectual disabilities exist? In this context, how does research and methodology become disempowering and disabling?
2. How does a training on research contribute to the quality of participation?
3. What content will be included in the training?

The term co-researcher will be used in this paper to refer to researchers with intellectual disabilities in participatory research projects, while acknowledging that in the literature the term and its definition varies.

Participatory research with persons with intellectual disabilities

PR differs from conventional research in where the power lies (Cornwall & Jewkes, 1995). Within traditional research methodologies, the researcher holds control over the entire research process (to the extent possible). Within PR, co-researchers are included to different degrees in the research process, and are given power over some or all phases of the project. While traditional research does not expose the process as much as PR does, PR requires explicitly addressing questions of power, of accessibility and transparency in this process. The reason for this is threefold: it assists the academic researchers in their reflexive process, it allows participants to get a clear picture of how they are being involved and it allows readers to assess the participatory nature, rather than a 'puppet management' or tokenistic use of participants, as criticized by earlier papers (Atkinson et al. 2000 cited Nind, 2011).

This requires exposing the decisions to be made in an accessible manner, and in a way that the co-researchers understand the relevancy of these decisions. There is a longstanding discussion around the differences between inclusive, participatory and emancipatory research with regards to the participation of persons with intellectual disabilities (Gjermestad, Luteberget, Midjo, & Witsø, 2019). Authors have classified the different forms of participation depending on the intensity of involvement (Frankena et al., 2018). Within inclusive research, which refers to PR with persons with intellectual disabilities, three forms of participation have been identified (Bigby, Frawley, and Ramcharan 2014b): establishing advisory boards which are consulted on different aspects of the research project (Bigby, Frawley, & Ramcharan, 2014a); leadership and control exercised by persons with intellectual disabilities; and a collaboration between persons with and without disabilities on equal terms.

Participation through advisory structures considers persons with intellectual disabilities 'expert by experience'. Power remains with the academic institution. There is a risk of only calling upon usual collaborators, e.g. self-advocates that are known from previous projects. The recruitment process gains more importance to ensure meaningful participant and that the participants are involved substantially in the research process, avoiding tokenism (Bigby, Frawley, & Ramcharan, 2014b).

The second form – leadership and control – confers more responsibility and power to persons with intellectual disabilities, who initiate, lead and execute their own research according to their priorities (Bigby et al., 2014b). The difficulty within lies in providing adequate and honest support to the researchers by non-disabled academic researchers (Nind, 2009). The concern is whether, when providing the support on how to conduct research, the person will (un)knowingly take over control over the research, defeating the whole purpose of PR.

The third option refers to collaborative research with people with intellectual disabilities and professional researchers (Bigby et al., 2014b). This approach is sometimes understood to be under the leadership of persons with intellectual disabilities (Walmsley and Johnson, 2003) or as a collaborative process, where academic researchers and co-researchers both have an active input into the process with shared and distinct purposes. Contributions from both are equally valued (Bigby et al., 2014b). It does not conceives professional researchers as simple helpers, but proposes a combination of skills and knowledge from persons with intellectual disabilities and researchers to produce new knowledge that neither could have done alone (Bigby et al., 2014b). The process of collaboration is especially valued, during which a relationship of trust and mutual learning is built (Nind, 2011) and equal attention is given to the different motivations. Research methods are usually adapted or transformed into group process, e.g. Nind's proposal of shared data analysis (Nind, 2011) or a dialogue conference (Gjermestad et al., 2019). This proposal is similar to the concept of collaborations in research (Katz & Martin, 1997). These authors find that while the most tangible parts of collaborative work can be measured, some cannot, e.g. a brilliant suggestion that defines latter steps in the research. Collaborations range from contributions of material, sharing data or ideas, through correspondence or visiting other institutions or performing parts of the project which are then put together by one of the researchers (Katz & Martin, 1997).

This last proposal solves the difficulty in the first two options of allowing for more abstract analysis and in depth writing, but requires substantive resources, e.g. money, time and commitment (Bigby et al., 2014b).

When is research disempowering and disabling?

Research and research methodology have been considered to contribute to the exclusion and disablement of persons with disabilities (Barton et al., 2018). This is one of the reasons why some authors called for participatory and emancipatory research. Notwithstanding, PR also entails risk of being disempowering and disabling. The written form and the use formal and technical language limit accessibility and participation. PR done without enough resources may lead to tokenistic involvement of persons (Bigby et al., 2014b). Further, the lack of accessibility of spaces, materials or the structuring of time may be a barrier to participate or to be connected to the project (Bigby et al., 2014b). Moreover, academic researchers often need to deal with the lack of independent living skills and technological skills of persons with intellectual disabilities that result from systemic discrimination (Ferreira & Díaz Velázquez, 2009). Being requested to have an opinion or work with issues without adequate support or not understanding the debated issues can also be disabling and disempowering (Bigby et al., 2014b). It is therefore key that academic co-researchers are transparent about the research process, engage in reflexive practice and seek feedback in different forms from co-researchers with disabilities. Alongside, some of these barriers can be removed through experience and by providing training on research (Fullana, Pallisera, Català, & Puyalto, 2017; Nind, 2011).

The importance of research skills

Persons with disabilities have historically been excluded from education and public life (Nind, 2011). Research and its purpose can be unknown to many, which makes it particularly difficult to engage with it. People with intellectual disabilities have been involuntarily involved in research (e.g. through proxy respondents, use of data by professionals for different purposes without consent) (Freedman, 2001) or have little to no experience participating in research, since they are often considered 'vulnerable' by ethics committees and excluded from samples (Horner-Johnson & Bailey, 2013).Seeking consent to participate in research becomes complex if the person does not understand what will happen with the data collected or why certain questions are asked. While information in advance might help to frame the purpose of the research, it is difficult to picture what will happen with what has been said or how it will affect the person in the future. A training will obviously not be able to predict the future, but it can help in providing information about what research does and facilitate the understanding of future invitations to participate in research.

In addition, previous research found that including training in research contributes to team building (Strnadová, Cumming, Knox, & Parmenter, 2014) and helps to become familiar with the language and reasoning used in research.

PR has been questioned with regards to the representativeness of co-researchers in relation to the (minority) group they are ascribed to in the researcher's mind (Bigby et al., 2014b). Previous research has found that it may be difficult to find appropriate participants among minorities or persons with a specific experience, due to lack of support or lack of skills (Bigby et al., 2014b). Therefore, providing training to those interested is a way of reaching out for participants for future projects and opening up options for more people, rather than involving always the same self-advocates or people.

Tokenism may occur for many reasons. For instance, if participants do not understand the decision being made, the issues debated and the relevant materials (Frawley & Bigby, 2011) or a lack of adequate support (Bigby et al., 2014b). Previous training can contribute to a better understanding of what issues are at stake within research.

PR projects have been criticised for lack of inclusion or weak participation during the data analysis phase (Nind, 2011). The literature shows that participation in the data analysis often neglected, due to lack of skills attributed to the participants (Nind, 2011), but also of the co-researchers who find it difficult to mediate or adapt the process. Different examples of co-researchers doing data analysis (discussing the emerging themes with participants or working in pairs after a training on how to look for themes in stories) shows that training in research skills can contribute to developing necessary skills, but is not sufficient to become a co-researcher (Nind, 2011). The research process itself is a learning process (Rioux et al. 2019). For some research projects, training was not an option as they wished co-researchers 'to find their own way to explore their life stories' (Holland et al. 2008 in Nind 2011). In this sense, this training proposal will not train in a specific methodology, but rather give a general sense of what research is and different ways of doing it.

The training proposal

The training is an introduction to why and how we do research, what ethical questions arise and different ways of approaching it. Researchers not related to the project will be invited to sit in each session to provide feedback on the content and training, as a way to counterbalance potential tendencies to influence participants. Not all participants in the trainings are expected to participate in future projects and there are no requirements other than interest to participate in the training. The modules are divided as follows:

1. What is research and why do we do research? Why participatory research?
2. This introductory session into research will give a general overview on why we do research with examples of research from disability studies and general socio-legal studies. I will also discuss PR, using examples from Spain and Ireland and how it is linked to the Convention on the Rights of Persons with Disabilities.
3. Elements of research.
4. In this section, I will talk about the different elements of a research project: research question, methodology, data collection, analysis and dissemination, and ethical implications, safety and anonymity. I will place special emphasis on the research question

and link it with different articles of the Convention on the Rights of Persons with Disabilities.

5. Quantitative research and qualitative research and examples:
6. In this session, I will talk about the differences between quantitative and qualitative research, with a special emphasis on the link to the research question, e.g. whether the purpose of the research is to look for causes, for opinions and experiences or to test possible solutions. This session will provide different examples of qualitative research, focusing on the differences, similarities and the importance of the participant sampling, depending on the research objective and research question. Examples from research in Spain will be shown (i.e. EDAD2008 survey on the situation of persons with disabilities) and drawing from qualitative research, I will present examples of research using life stories, interviews & focus groups.
7. Findings & analysing results:
8. The ways of holding the data collection will be presented, e.g. through transcripts, recordings, visual material will be presented. Data analysis will be discussed using examples from previous research, engaging in group discussions or with visual aids.
9. Forms of presenting findings & dissemination action:
10. In this session, we will discuss different forms of presenting findings: papers and conferences, reports, scholar or self-advocacy exchanges, videos, websites or as submissions to national and international policy makers. The limits of interpretation of research and the link between research, advocacy and change will be discussed.
11. Using new technologies to work together
12. Due to COVID 19, online tools are essential in case of lockdown or distance keeping. In this session, we will practice using online communication tools and holding discussions over these tools.

Conclusion

There are multiple forms of engaging people with intellectual disabilities in research as co-researchers. All options bring their own difficulties along. The lack of experience and research skills increases the risk of being exposed to undermining support and academic researchers taking over control. However, training is not the sole preparatory step to engage in participatory research. Academic researchers need to engage in a reflexive processes, be creative, seek feedback from co-researchers and ensure accessibility and an enabling working environment. Inviting other researchers to observe the trainings may reduce the risk of being too one-sided, exposes the research to critique and other perspectives and creates new connection opportunities for co-researchers. Training options and accessible research, conferences and academic events can potentially increase participation and engagement of persons with intellectual disabilities with research and *vice versa*. Lastly, open trainings are a way of expanding knowledge, networks and exploring new research possibilities.

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7 Disability in court: a method for case law systematization

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Abstract

This paper presents a method for the systematization of a large sample of case law based on the core legal issues assessed in the selected judicial decisions. The study aims to highlight the usefulness of the proposed approach in examining prevailing topics, trends in judicial reasoning and concepts applied when conducting a textual analysis of case law. The discussion is based on a larger-scale study which provides a doctrinal analysis of the manner in which courts in England and Wales frame the concept of disability when adjudicating employment-related claims. The analysis in the present study focuses on a small randomly selected sample of case law located through systematic key-word searches in the online database West Law UK. While the present study centers on the concept of disability, the method can be applied to a wide variety of case law samples where the aim of the author is to analyze how courts frame a specific issue or concept through textual analysis. It is argued that the proposed method of systematizing case law allows for a streamlined grouping of the selected judicial decisions which can facilitate an examination into the uniformity with which courts apply the same or similar legal frameworks across a large number of cases. The method also can allow to tracing common concepts courts use to frame a particular concept or issue, as well as prevailing topics of interest, to flesh out specific types of claims where such concepts and topics are discussed and to compare the judicial framing adopted therein in a streamlined manner.

Introduction

This paper presents a method for the systematization of a large sample of case law based on the core legal issues assessed in the selected judicial decisions. The study aims to highlight the usefulness of the proposed approach in examining prevailing topics, trends in judicial reasoning and concepts applied when conducting a textual analysis of case law. The discussion is based on a larger-scale study which provides a doctrinal analysis of the manner in which courts in England and Wales frame the concept of disability when adjudicating employment-related claims. This focus is used to exemplify the application of the method to case law analysis by outlining the method, as well as some preliminary insights into its application. The analysis in the present study focuses on a small randomly selected sample of case law. The discussion proceeds in the following manner. Firstly, the term (judicial) ‘framing’ is defined for the purposes of the study. Secondly, a description of the approach taken to select the case law sample is provided. Then, the method for case law systematization is presented as it was applied to systematization the selected judicial decisions. Finally, the study provides two preliminary insights into some of the prevailing topics of discussion and concepts used by courts in framing the issue of disability in an employment context. The objective is to highlight the application of the proposed method for systematization to trace common threads of reasoning within a case law sample.

Definition of Judicial Framings

The present study centers on how courts frame disability, i.e. the concept of judicial framing. This term is used in varying ways across different disciplines. For instance, in behavioral economics, the concept of ‘framing’ refers to the phenomenon of loss aversion, i.e. whether individuals consider, or frame, a choice or a situation as a loss or as a gain.[1] In the context of judicial decision making, framing, therefore, refers to the manner in which judges react to perceived losses or gains when adjudication legal disputes.[2] In socio-legal and sociological scholarship on legal/judicial framings, the term 'framing' is used in relation to social movements; in turn, the term 'legal framings' refers to the manner in which 'law shapes [social movements] activists' perceptions, tactics and ability to generate social change'.[3] Although there are important differences in how the two fields of scholarship conceptualize the term legal framing,[4] judicial framings of disability in this context can broadly be defined as the manner in which courts influence the capacity of the disability movement to contribute to social change regarding the perception of disability in society.

All of these fields of scholarship can provide theoretical frameworks for explaining how judges frame disability in a specific way, and why they adopt one framing of disability over another. However, such an explanation is not the aim of the present paper. This study aims instead to provide a method for systematizing judicial decisions which provide a framing of disability; therefore, the aim is not to explain the reasons why judges adopt specific framings of disability in the selected case law sample or to provide a detailed analysis of the process of how judges arrive at these framings. This analysis may flow at a later stage from the systematization of the selected decisions. For this reason, the study adopts a definition of the term 'framing' that is based on the conceptualization of the term by Wedeking.[5] Wedeking defines the term 'frame' to mean 'a small collection of related words that emphasize some aspects of an issue at the expense of others' and the term 'framing' as 'the selection of one particular frame over another'.[6] On this basis, the discussion of judicial framings of disability in employment in this study focuses on prevailing words/concepts used in the case law and key topics assessed used by judges in discussing disability. This focus is intended to provide a method for tracing common threads of judicial reasoning in analyzing a large case law sample.

The Selected Case Law Sample

The method of case law systematization presented here was developed with the intention to be applied to an analysis of a large sample of judicial decisions framing the concept of disability produced by courts in England and Wales in an employment context in the period of 1995-2020. This period was selected due to the entry into force of a disability-specific piece of legislation in the domestic system of the UK, the Disability Discrimination Act 1995,

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[1] Jeffrey J. Rachlinski and Andrew J. Wistrich, 'Gains, Losses, and Judges: Framing and the Judiciary' (2019) 94 Notre Dame Law review 521, 523.

[2] *Ibid* 528.

[3] Gwendolyn Leachman, 'Legal Framing' (2013) 61 Studies in Law, Politics, and Society 25, 26.

[4] *Ibid* 27-29.

[5] Justin Wedeking, 'Supreme Court Litigants and Strategic Framing' (2010) 54 American Journal of political Science 617.

[6] *Ibid* 617.

and its later replacement by the Equality Act 2010.[7] For the purpose of developing the method of case law systematization, the author decided to conduct a pilot study of a part of the case law sample, focusing on the period of 2010-2020. The case law sample was located through systematic key-word searches in the online database West Law UK. The key words used therein were 'disability', 'disabled' and 'disablement'. The field of interest selected was 'employment' and the selected jurisdiction was 'United Kingdom, England and Wales'. These searches yielded 60 results, out of which a case law sample of 17 cases was randomly selected for a close reading a doctrinal analysis. The analysis focused specifically on the manner in which disability is framed, the prevailing legal issues assessed in the case law, as well as what overarching words and topics are used for the discussion of disability. On this basis, the researcher developed the following method to systematize these 17 decisions.

The Method for Case Law Systematization

The method proposed here focuses on the central legal claim assessed in each of the selected cases, as well as on the legal framework applied by the courts therein. On this basis the decisions were separated into 4 clusters of claims. Following an analysis of the larger case law sample, all of the cases selected will be organized according to this method. The four Clusters designed so far are the following: 1. Claims concerning entitlement to an injury on duty award; 2. Tort and breach of contract claims; 3. Claims challenging disciplinary measures for alleged workplace misconduct; and 4. Miscellaneous claims.

Decisions grouped in Cluster 1 concern claims brought by former police officers under the legal framework of the Police (Injury Benefit) Regulations 2006, which provide that a police officer is entitled to receive an injury on duty award upon retirement from the police force whereby they have acquired a disability as a result of injuries received in the execution of their duties. To determine whether an officer is entitled to such an award, the courts in the reviewed decisions frame the issue of disability by applying a causation test to establish whether an injury was acquired in the execution of a police officer's duties and thus amounts to a disability.[8]

Cluster 2 concerns claims brought against a former employer for an alleged tort or breach of contract as a result of which the claimant has acquired a disability. The cases encompass two sets of claims: firstly, stress-at-work claims (referring to psychological injuries received as a result of workplace harassment),[9] and secondly, claims concerning physical disabilities which

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[7] Anna Lawson, 'Disability and Employment in the Equality Act 2010: Opportunities Seized, Lost and Generated' (2011) 40 Industrial Law Journal 359, 359.

[8] See, for example, *Chief Constable of Avon and Somerset Constabulary v Police Medical Appeal Board* [2019] EWHC 557 (Admin), para 17; *R. (on the application of Boskovic) v Chief Constable of Staffordshire* [2018] EWHC 14 (Admin), paras 22-38; 95; *R. (on the application of Sidwell) v Police Medical Appeal Board* [2015] EWHC 122 (Admin), paras 9, 13-14.

[9] *Bailey v International Automotive Components Group Ltd* [2014] WL 5833810; *Manda v USB AG* [2016] WL 03268506.

are alleged to have occurred as a result of hazardous working conditions.[10] The case law stipulates several legal tests to establish whether the claimant is disabled for the purposes of financial compensation, including a test of the foreseeability of harm,[11] a test establishing whether the claimant is appreciably worse off due to the injury suffered,[12] a causation test to establish whether the disability acquired is the result of hazardous working conditions,[13] and a test establishing the limits of the employer's duty of care in relation to the acquisition of a disability.[14]

Cluster 3 concerns appeals against decisions by specialized tribunals imposing disciplinary sanctions for alleged workplace misconduct by an employee in the course of their employment and/or for an alleged impairment of an employee's fitness to practice. The decisions can be separated into two sets of claims based on the discussion of disability. The first set concerns appeals brought by a disabled employee whereby the tribunal's finding of misconduct is related or is alleged to be related to the claimant's disability.[15] The second set of decisions concerns appeals against imposed disciplinary sanctions for alleged misconduct towards a person with a disability.[16]

The final Cluster includes two cases which do not fit within the legal context of the other claims. These two decisions have not been examined for the purposes of the present paper. One case does not provide any substantial treatment of disability,[17] while the second decision concerns a claim for a war disablement pension, which has been excluded from the present discussion due to the specifics legal framework applicable.[18] The latter claim may form a separate Cluster if more cases under the same legal framework are examined when the entire case law sample is assessed.

Preliminary Insights into the Case Law

This classification of case law on the basis of the core legal issue assessed in each decision provides a streamlined approach to trace common patters in the concepts and topics discussed by judges in framing disability in employment. Grouping the cases in this manner allows the researcher to review how courts apply the same or similar legal frameworks and whether there is uniformity in this application depending on the type of disability assessed during the

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[10] *Holloway v Tyne Thames Technology Ltd* [2015] WL 5037777; *Prater v British Motor Holdings Ltd* [2016] WL 03947474; *Camden v Jackpot Leisure Ltd* [2015] WL 13639235: this claim encompasses several grounds which relate to the alleged employer's negligence, including a discussion whether an employer has a duty of care to prevent harm occurring on the premises of a third party.

[11] *Bailey* (n 9) para 20.

[12] *Holloway* (n 10) paras 10-11.

[13] *Prate*r (n 10) paras 21-28.

[14] *Camden* (n 10) paras 14-16.

[15] *Jain v General Medical Council* [2019] EWHC 1841 (Admin*); McDermott v Health and Care Professions Council* [2017] EWHC 2899 (Admin); *General Medical Council v El Huseini* [2014] EWHC 3736 (Admin).

[16] *Craig v Farriers Registration Council* [2017] EWHC 707 (Admin); *Jain* (n 11).

[17] *R. (on the application of Justice for Health Ltd) v Secretary of State for Health* [2016] EWHC 2338 (Admin).

[18] *R. (on the application of Rogerson) v Secretary of State for Defence* [2012] EWHC 2131 (Admin).

proceedings. Moreover, this method of systematization allows the researchers to examine whether specific concepts are used in the framing of disability in a specific type of claim or in reference to specific types of disabilities. To exemplify these two points, the following paragraphs discuss the concept of 'vulnerability' and compare the treatment of physical and psychological disabilities applied in the sample.

'Vulnerability' is an important concept for the manner in which disability is framed in several decisions which deal with claims for financial compensation. In three such decisions reference to 'vulnerability' is made to reject the assertion that the claimant is disabled for the purpose of receiving monetary compensation for an acquired disability. In *Sidwell* a selected medical practitioner (SMP) concludes that the claimant is not disabled and that his symptoms are 'due to vulnerability rather than disablement' and the court rejects the claimant's appeal for review of his entitlement to an injury award.[19] Similarly, in *Avon and Somerset* the SMP who assesses whether a former police officer is disabled for the purpose of being entitled to an injury award concludes that he is not disabled and instead has a 'vulnerability' caused by personality traits.[20] The court in *Bailey* strongly rejects that the claimant is disabled due to alleged workplace harassment, instead concluding that he is 'vulnerable' due to personality traits which cause him to misinterpret his employment circumstances.[21] In light of these preliminary findings, the proposed case law systematization can allow the author to discuss whether claims for injury awards and tort or breach of contract claims are framed by juxtaposing 'disability' and 'vulnerability' and whether this has a bearing on the court's decision as to whether the claimant is disabled and is to the financial detriment to persons with disabilities.

A first analysis of the case law sample has also revealed that there may be a difference in how courts frame physical and psychological disabilities. Some courts, when dealing with claims concerning the acquisition of psychological disabilities, attribute such disabilities to a personality defect, such as 'vulnerability' or 'family history'. For example, in *Boskovic*, despite the claimant having suffered assaults in the execution of her duties as a police officer, emphasis is placed on '[a] positive family history of mental illness'.[22] In *Sidwell*, despite expert evidence that the claimant became disabled due to his workplace situation,[23] the court refers to 'feelings of anger, resentment, embitterment, and antipathy by the claimant towards his employer' as a cause for his symptoms,[24] and his anxiety is determined not to be disabling.[25] In *Bailey* the court traces the issue to the claimant's personality traits and rejects that the claimant is disabled due to workplace harassment (see above). In contrast, claims concerning physical disabilities are not framed in the context of whether the claimant is

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[19] *Sidwell* (n 8) para 23.
[20] *Avon and Somerset* (n 8) para 8.
[21] *Bailey* (n 9) paras 35-37, 100, 103-104.
[22] *Boskovic* (n) para 48.
[23] *Sidwell* (n 8) para 22.
[24] *Ibid* para 16.
[25] *Ibid* para 18.

disabled or is ‘vulnerable’ or has a ‘family history’ of disability. The courts in these cases apply a variety of tests to determine whether the claimant is entitled to a compensation (see above) but do not frame the issue by ‘faulting’ the claimant for the symptoms described in the claims. In this context the proposed method can allow the researcher to further explore whether there is a difference in how courts frame different types of disabilities. Moreover, it will allow an assessment of whether the legal framework under which different claims fall and the legal tests applied therein to determine the existence of a disability have a bearing on whether the claimant is found to be disabled.

Conclusion

The method for case law systematization proposed in this study is a useful tool for the systematic analysis of a large sample of judicial decisions through textual analysis. While the present study centers on the issue of judicial framings of disability in employment adopted by English and Welsh courts, the method can be applied to a wide variety of case law samples where the aim of the author is to analyze how courts frame a specific issue or concept through textual analysis. It allows for a streamlined grouping of the selected case law based on the central legal claim to the dispute. On this basis, the researcher can assess whether courts apply the same or similar legal frameworks in a uniform manner across a large number cases, as well as to outline patter so divergence in this application. Moreover, the method allows for common concepts courts use to frame a particular concept or issue, as well as prevailing topics of interest, to be traced with greater ease. The method also allows the researcher to flesh out specific types of claims where such concepts and topics are discussed and to compare the judicial framing adopted therein in a streamlined manner.

8 Supporting people with psychosocial and intellectual disabilities with communication during court proceedings

Edmore Masendeke

Abstract

This chapter explores the extent to which people other than their legal advisors assist people with psychosocial and intellectual disabilities with communication in criminal court in England and Ireland. Beyond describing the type of support providers which are available in both jurisdictions, the application of the support which is available in England is compared and distinguished from that which is available in Ireland. In England, people with psychosocial and intellectual disabilities receive communication support from the Witness Service, intermediaries and non-formal support providers such as carers, friends, support workers and advocates. The same type of support is available in Ireland except the Witness Service. Legislation in both countries categorise people who require procedural accommodations as vulnerable witnesses, those who are the focus of this chapter and deny defendants equal access to procedural accommodations. Furthermore, the definition and application of the role of an intermediary and legal professionals' attitudes to special measures are not the same in England and Ireland.

Introduction

Previous research shows that people with psychosocial and intellectual disabilities face barriers to giving evidence and understanding what is happening in criminal court. Such barriers include the use of questioning techniques which affect the accuracy of their evidence[1] and being expected to provide details such as dates, times and colours in specific formats when giving eyewitness evidence.[2] Another common barrier is the formality and complexity of the language used in court as people with psychosocial and intellectual disabilities sometimes have limited knowledge or understanding of legal terminology; the roles of legal professionals and other court participants; and court procedures.[3] From a social model perspective, these barriers must be removed in order for people with psychosocial and intellectual disabilities to participate effectively in criminal court. As such, article 13 of the Convention on the Rights of Persons with Disabilities (CRPD) requires State Parties to ensure 'effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations.' The

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[1] William ML Finlay and Evanthia Lyons, 'Acquiescence in interviews with people who have mental retardation' (2002) 40(1) Mental retardation 14.

[2] Mark R. Kebbell, Christopher Hatton and Shane D. Johnson, 'Witnesses with intellectual disabilities in court: What questions are asked and what influence do they have?' (2004) 9(1) Legal and Criminological Psychology 23.

[3] Kristine I Ericson and Nitza B Perlman, 'Knowledge of legal terminology and court proceedings in adults with developmental disabilities' *Law and Human Behavior* 25.5 (2001): 529-545.

interpretation of article 13 that has been proffered by the CRPD Committee demonstrates that procedural and age-appropriate accommodations include support for communication during court proceedings. For example, the CRPD Committee requested Chile,[4] Uruguay,[5] Honduras[6] and Panama[7] to provide live, personal or intermediary assistance 'to ensure that persons with disabilities can effectively participate, in various capacities, in legal proceedings.'

This chapter explores the extent to which people other than their legal advisors assist people with psychosocial and intellectual disabilities with communication in criminal court in England and Ireland. Beyond describing the type of support providers which are available in both jurisdictions, the application of the support which is available in England is compared and distinguished from that which is available in Ireland. The remainder of this chapter is divided into three sections. In section two is a discussion the type of support providers which are available in England and Ireland. In section three is a comparison of the application of this support. Finally, section four is the conclusion.

As a final preliminary note, the terminology that is used in this chapter is widely used by countries and organisations, including representative organisations working for human rights and equality of the people concerned. This includes the World Network of Users and Survivors of Psychiatry for people with psychosocial disabilities and Inclusion International for people with intellectual disabilities. The term 'people with psychosocial disabilities' refers to people who have used mental health services,[8] 'those who have experience of mental health issues and/or identify as mental health users,'[9] including people 'who do not identify as persons with disability but have been treated as such, e.g., by being labelled as mentally ill or with any specific psychiatric diagnosis.'[10] The term 'people with intellectual disabilities' refers to individuals whose intellectual and adaptive skills have been impaired since childhood. However, alternative terms will used and explained in direct quotations or where context requires.

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[4] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of Chile' (2016) CRPD/C/CHL/CO/1, para 28.

[5] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of Uruguay' (2016) CRPD/C/URY/CO/1, para 30.

[6] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of Honduras' (2017) CRPD/C/HND/CO/1, para 32.

[7] UN Committee on the Rights of Persons with Disabilities, 'Concluding observations on the initial report of Panama' (2016) CRPD/C/PAN/CO/1, para 33(a).

[8] Fleur Beaupert, 'Freedom of opinion and expression: From the perspective of psychosocial disability and madness' (2018) 7(1) Laws 3.

[9] Louise Ellison, Vanessa E Munro, Katrin Hohl and Paul Wallang, 'Challenging criminal justice? Psychosocial disability and rape victimization' (2015) 15(2) Criminology & Criminal Justice 225, 228.

[10] World Network of Users and Survivors of Psychiatry, 'Psychosocial disability' (2008) World Network of Users and Survivors of Psychiatry available at <http://www.wnusp.net/index.php/crpd.html> accessed 11 April 2020.

Communication support provided to people with psychosocial and intellectual disabilities in the criminal courts in England and Ireland

In this chapter, the term ‘communication’ is used to refer to court users’ communication with the court in literal terms, that is, giving evidence in court, and their understanding of announcements, court proceedings, instructions and ‘all other processes involving the participation of court.’[11] Thus, people who support people with psychosocial and intellectual disabilities with communication in any of these ways are the focus of this section. This includes support which provided before, during and after trial within the vicinity of the court.

As this chapter focuses on support in two countries, I will first discuss the support that is available in England, then in Ireland. In England, people with psychosocial and intellectual disabilities receive communication support from the Witness Service, intermediaries and non-formal support providers such as carers, friends, support workers and advocates. The same type of support is available in Ireland except the Witness Service. However, this support is provided to different extents in the two jurisdictions as discussed in the next section. The remainder of this section, however, discusses how each of these support providers assist people with psychosocial and intellectual disabilities and draws upon previous empirical research on the experiences of people with psychosocial and intellectual disabilities in the criminal justice system to demonstrate the impact of this support on the participation of people with psychosocial and intellectual disabilities in criminal court proceedings. In some cases, I refer to evidence about the experiences of disabled people in general due to the lack of research on the experiences of people with psychosocial and intellectual disabilities on the subject.

Communication support provided in England

As mentioned above, people with psychosocial and intellectual disabilities in England receive communication support from the Witness Service, intermediaries and non-formal support providers such as carers, friends, support workers and advocates. Support from the Witness Service, a national service provided by the charity Victim Support, is not only available to people with psychosocial and intellectual disabilities, but to all witnesses who attend trial in every Crown Court centre and magistrates’ court in England and Wales. However, it is only available to victims and witnesses. While a detailed discussion of the services of the Witness Service is beyond the scope of this paper, they include providing information, pre-court familiarisation tours and explanations about court proceedings.[12] Other services include

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[11] Eilionóir Flynn, *Disabled Justice?: Access to Justice and the UN Convention on the Rights of Persons with Disabilities* (Ashgate Publishing 2015).

[12] Citizens Advice Bureau, ‘Citizens Advice witness service: Partners update – First edition’ Citizens Advice Bureau <https://www.citizensadvice.org.uk/Global/Migrated_Documents/corporate/partner-readiness-pack---final.pdf> accessed 21 August 2020.

facilitating witnesses receiving regular updates on the progress of their trial and an explanation about the outcome of the trial from the appropriate person if necessary.[13]

In 2010, the Ministry of Justice published a series of reports on the court experience of adults with mental health conditions (psychosocial disabilities), learning disabilities (intellectual disabilities) and limited mental capacity. People with psychosocial and intellectual disabilities who participated in these studies reported that they appreciated the support that they had received from the Witness Service, particularly clarification about the court documents which were sent to them before trial, court familiarisation tours or pre-trial visits, assistance with writing tasks, explanations of the court process and updates of the proceedings both before and during trial.[14] While Witness Service staff are expected to provide passive support during court proceedings, the researchers report of Witness Service staff members who have recommended special measures for witnesses and received reprimands from judges.[15]

Special measures refer to procedural accommodations which the court may make to enable a witness who is below 18[16] or an adults who has a cognitive[17] or physical impairment[18] which is likely to diminish the quality of their evidence to give their best evidence under the Youth Justice and Criminal Evidence Act 1999. This include the use of intermediaries,[19] among other accommodations.[20]

Intermediaries facilitate communication between the witness and the court by ensuring that the witnesses understand the questions that he or she is asked, and the court understands the witness' answers during court proceedings.[21] Most intermediaries are specialised

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[13] Citizens Advice Bureau, 'Citizens Advice witness service: Partners update – First edition' Citizens Advice Bureau <https://www.citizensadvice.org.uk/Global/Migrated_Documents/corporate/partner-readiness-pack---final.pdf> accessed 21 August 2020.

[14] Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental health conditions, learning disabilities and limited mental capacity' (Report 2: Before court overview and recommendations, Ministry of Justice research series 9/10, Ministry of Justice 2010); Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental health conditions, learning disabilities and limited mental capacity' (Report 3: At court, Ministry of Justice research series 10/10, Ministry of Justice 2010).

[15] Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental health conditions, learning disabilities and limited mental capacity' (Report 3: At court, Ministry of Justice research series 10/10, Ministry of Justice 2010).

[16] Youth Justice and Criminal Evidence Act 1999, s 16(1)(a).

[17] Youth Justice and Criminal Evidence Act 1999, s 16(2)(a)(i), 16(2)(a)(ii).

[18] Youth Justice and Criminal Evidence Act 1999, s 16(2)(b).

[19] Youth Justice and Criminal Evidence Act 1999, s 29.

[20] This includes screening witness from the accused (s 23); giving evidence in private (s 25); the removal of wigs and gowns (s 26); giving evidence via a live television link (s 24); the admission of video recorded evidence-in-chief (s 27) and cross-examination (s 28); the use of communication aids during criminal court proceedings (s 30).

[21] Youth Justice and Criminal Evidence Act 1999, s 16.

communication specialists who are trained and accredited under the Ministry of Justice's Witness Intermediary Scheme. While it was initially restricted to non-defendant witnesses (plaintiffs and witnesses) only, the use of intermediaries has, in recent years and to a limited extent, been extended to defendants as well following the insertion of s 33A and s 33B in the Youth Justice and Criminal Evidence Act 1999 by the Coroners and Justice Act 2009 s 104. However, these provisions are is yet in force. Nevertheless, the use of an intermediary as a defendant has in some instances been allowed based on judicial discretion[22] in terms of paragraph 3F.13 of the Criminal Practice Direction.

Since the introduction of intermediaries in English and Welsh courts in 2004, there has been growing research on the experiences of intermediaries and other stakeholders, including the people who have used intermediaries and their carers. For example, in 2007, Plotnikoff and Woolfson conducted an evaluation of intermediaries and found that 'almost all those who encountered the work of intermediaries in pathfinder cases expressed a positive opinion of their experience.'[23] The 2010 reports that were published by the Ministry of Justice mentioned above also highlighted that some people with learning disabilities (intellectual disabilities) confirmed that they had used intermediaries and reported that it increased their understanding of court proceedings.[24] However, the effectiveness of intermediaries was sometimes limited by 'late applications', 'poor coordination' and 'unrealistic expectations.'[25] Furthermore, research suggests that intermediaries are not sure about how to assist defendants as this is not addressed in their training.[26] This notwithstanding, the role of an intermediary is sometimes carried out by a person with no training and accreditation from the Ministry of Justice in cases involving defendants due to the lack of adequate provision for them to gain access to the services of an intermediary with the training and accreditation.[27]

In addition to Witness Service volunteers and intermediaries, non-formal support providers, such as carers, friends, support workers and advocates, can also assist people with psychosocial and intellectual disabilities with communication in court. Like Witness Service staff, they are only allowed to provide passive support during court proceedings and explain

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[22] see *C v Sevenoaks Youth Court* [2009] EWHC 3088.

[23] Joyce Plotnikoff and Richard Woolfson, 'The 'Go-Between': evaluation of intermediary pathfinder projects' (Office for Criminal Justice Reform 2007) vi.

[24] Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental heaslth conditions, learning disabilities and limited mental capacity' (Report 3: At court, Ministry of Justice research series 10/10, Ministry of Justice 2010).

[25] Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental health conditions, learning disabilities and limited mental capacity' (Report 3: At court, Ministry of Justice research series 10/10, Ministry of Justice 2010) i.

[26] Rebecca Milne, Ray Bull, Brendan M O'Mahony, Jane Creaton and Kevin Smith, 'Developing a professional identity in a new work environment: the views of defendant intermediaries working in the criminal courts' (2016) Journal of Forensic Practice.

[27] 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 4.

what takes place in the courtroom during breaks or after the hearing.[28] McLeod and colleagues found that some carers and support workers are unfamiliar with court language and practices and face difficulties explaining them too.[29]

Communication support provided in Ireland

In Ireland, people with psychosocial and intellectual disabilities can receive support from intermediaries and non-formal support providers such as carers, friends, support workers and advocates. While intermediaries are well established in England, as they have been in use since 2004,[30] in Ireland, an intermediary was first used in court in 2015[31] despite being statutorily prescribed since 1992. Scholars attribute the under-utilisation of intermediaries in Irish courtrooms to the reluctance of legal professionals to rely on special measures;[32] fears of the intermediary influencing the witness's response;[33] and the lack of clarity on who should fulfil this role and how.[34] The latter could be due to the fact that there is no statutorily prescribed definition of an intermediary in Ireland, as is the case in England and Wales. As such, family, friends and advocates serve as intermediaries in Ireland[35] on an 'ad hoc' basis.[36] Furthermore, only non-defendant witnesses are entitled to intermediaries.[37] As the use of intermediaries in Ireland is in its early stages, empirical research on the subject is currently very limited and none of it discusses the experiences of people with psychosocial and intellectual disabilities in particular.

While they sometimes act as intermediaries, carers, friends, support workers and advocates are 'vital to enable people with disabilities to report crimes and follow the case through.'[38]

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[28] Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental health conditions, learning disabilities and limited mental capacity' (Report 3: At court, Ministry of Justice research series 10/10, Ministry of Justice 2010);

[29] Rosie McLeod, Cassie Philpin, Anna Sweeting, Lucy Joyce and Roger Evans, 'Court experience of adults with mental health conditions, learning disabilities and limited mental capacity' (Report 3: At court, Ministry of Justice research series 10/10, Ministry of Justice 2010).

[30] Joyce Plotnikoff and Richard Woolfson, *The 'Go-Between': evaluation of intermediary pathfinder projects* (Ministry of Justice 2007).

[31] DPP v FE [2015] unreported, (Hunt J) (Bill No. 84/2013 Central Criminal Court).

[32] Alan Cusack, 'Victims of crime with intellectual disabilities and Ireland's adversarial trial: some ontological, procedural and attitudinal concerns' (2017) 68(4) Northern Ireland Legal Quarterly 433; Alan Cusack, 'Addressing vulnerability in Ireland's criminal justice system a survey of recent statutory developments' (2020) International Journal of Evidence & Proof 1 (Forthcoming).

[33] Claire Edwards, Gillian Harold and Shane Kilcommins, 'Access to Justice for People with Disabilities as Victims of Crime in Ireland' (National Disability Authority 2012) 113.

[34] See Rape Crisis Network Ireland (2018: 10).

[35] Claire Edwards, Gillian Harold and Shane Kilcommins, 'Access to Justice for People with Disabilities as Victims of Crime in Ireland' (National Disability Authority 2012) 113.

[36] Law Reform Commission, *Sexual offences and capacity to consent* (Law Reform Commission 2013) 108.

[37] Criminal Evidence Act 1992 (Ireland) s 14

[38] Claire Edwards, Gillian Harold and Shane Kilcommins, 'Access to Justice for People with Disabilities as Victims of Crime in Ireland' (Faculty of Law, University College Cork 2012) <https://www.ucc.ie/en/media/academic/law/ccjhr/publicationsseptember2018/AccesstoJusticeforPeoplewithDisabilitiesasVictimsofCrimeinIreland2012.pdf> accessed 12 June 2020.

Edwards and colleagues report of an organisation that assisted a person with intellectual disabilities in pursuing their case:

> one service provider noted that a particular individual with intellectual disabilities would not have ended up pursuing their case if they had not supported them through what proved to be a lengthy process, and that people with disabilities would be at a particular disadvantage if they did not have an organisation or some other party advocating for them.

While the type of support that was provided is described as 'advocating for them', this story is told as part of a discussion on the lack of clarity about the role of an intermediary and disabled people's need for assistance in reporting crimes and attending court. Thus, the support that was provided may have encompassed support with communication in terms of explaining the processes involved in the participation of court and what was happening in court.

Comparison of the communication support which is support available in England and Ireland

In the previous section, it was established that while there are intermediaries and non-formal support providers in both England and Ireland, the Witness Service also supports people with psychosocial and intellectual disabilities with communication in criminal courts in England. Beyond this, there are other similarities and differences in the application of the support which is available in England and Ireland. In both countries, people who require procedural accommodations such as support with communication in court are categorised as 'vulnerable witnesses.' In addition, pathologising terminology is used to refer to categories of disabled people which include those who are the focus of this chapter and defendants are entitled to less support than complainants and witnesses in both countries. However, the definition and application of the role of an intermediary and legal professionals' attitudes to special measures are not the same in England and Ireland. These similarities and differences are discussed in greater detail below.

People who require procedural accommodations are categorised as 'vulnerable' in statutory provisions for special measures such as support with communication in court in both England[39] and Ireland.[40] In these provisions, vulnerability is defined with reference to a person's age and impairment. Defining vulnerability with reference to a person's impairment is problematic as it can be used to oversimply the lived experiences of the disabled people by assuming that they are inherently vulnerable, which is not the case, and neglect other factors that contribute to their vulnerability.[41] Defining vulnerability with reference to a person's

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[39] Youth Justice and Criminal Evidence Act 1999, s 16(2)(a)(ii).

[40] Criminal Evidence Act 1992, as amended by the Criminal Justice (Victims of Crime) Act 2017, s 19.

[41] Florencia Luna, 'Elucidating the concept of vulnerability: Layers not labels' (2009) 2(1) International Journal of Feminist Approaches to Bioethics 121; Alan Cusack, 'Addressing vulnerability in Ireland's criminal justice system a survey of recent statutory developments' (2020) International Journal of Evidence & Proof 1 (Forthcoming).

impairment also has the danger of reinforcing stereotypical attitudes towards disabled people and undermining their credibility as witnesses in the criminal justice system. Roulstone and colleagues argue that reference to disabled people as vulnerable 'unhelpfully ensures that safeguarding and adult protection measures often take precedence over criminal justice responses where disabled identities are constructed as vulnerable, at risk, thus denying many disabled people the right to be taken seriously in the criminal justice system....'[42] In addition, some categories of disabled people such as people with psychological and intellectual disabilities may 'face a serious credibility challenge in seeking, on the one hand, to demonstrate their vulnerability for the purpose of being granted a special accommodation in court without, on the other hand, cultivating an ethic of unreliability in the eyes of the jury.'[43]

In addition to categorising people who require procedural accommodations as vulnerable, legislation in both countries uses pathologising terminology to refer to categories of disabled people which include people with psychosocial and intellectual disabilities. Under the Youth Justice and Criminal Evidence Act 1999 of England and Wales, special measures may be extended to an adult who 'suffers from mental disorder'[44] or 'has a significant impairment of intelligence and social functioning.'[45] Under the Criminal Evidence Act 1992 of Ireland, special measures can be extended to people with 'mental handicap.'[46] The Criminal Justice (Victims of Crime) Act 2017, however, has replaced the term 'mental handicap' with 'mental disorder'[47] in some provisions of the Criminal Evidence Act 1992[48] but this new terminology is no less pathological. Thus, this language encourages a diagnostic approach to the provision of procedural accommodations.[49] Accordingly, Cusack has criticised the use of the terms 'mental handicap' and 'mental disorder' in Irish legislation and described it as 'pejorative', 'outdated' 'grounded in a presumption of incompetence' and 'disempowering.'[50]

Beyond the categorisation and terminology issues, defendants' lack of access to procedural accommodation is also a common concern in both countries. In England, plaintiffs and

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[42] Alan Roulstone, Pam Thomas, and Susie Balderston, 'Between hate crime and vulnerability: unpacking the British criminal justice system's construction of disablist hate crime' (2011) 26 (3) Disability and Society 351, 352.

[43] Alan Cusack, 'Addressing vulnerability in Ireland's criminal justice system a survey of recent statutory developments' (2020) International Journal of Evidence & Proof 1 (Forthcoming).

[44] Youth Justice and Criminal Evidence Act 1999 s 16(2)(a)(i).

[45] Youth Justice and Criminal Evidence Act 1999 s 16(2)(a)(ii).

[46] Criminal Evidence Act 1992 s 19.

[47] Criminal Evidence Act 1992 s 19 as amended by s 30(l)(iii) of the Criminal Justice (Victims of Crime) Act 2017.

[48] The term 'mental handicap' still appears in the title of s 19 of the Criminal Evidence Act 1992 and in provisions for unsworn evidence (Criminal Evidence Act 1992 s 27(3))

[49] Fleur Beaupert, 'Freedom of opinion and expression: From the perspective of psychosocial disability and madness' (2018) 7(1) Laws 3.

[50] Alan Cusack, 'Victims of crime with intellectual disabilities and Ireland's adversarial trial: some ontological, procedural and attitudinal concerns' (2017) 68(4) Northern Ireland Legal Quarterly 433; Alan Cusack, 'Addressing vulnerability in Ireland's criminal justice system a survey of recent statutory developments' (2020) International Journal of Evidence & Proof 1 (Forthcoming).

witnesses have access to the special measures provided for in the Youth Justice and Criminal Evidence Act 1999, while defendants only have limited access to the use of live television link and intermediaries.[51] In the latter case, most defendants only receive support for giving evidence and not the rest of the court proceedings.[52] In Ireland, only non-defendant witnesses are entitled to most of the special measures.[53] In particular, defendants have no right to an intermediary under Ireland's current statutory provisions.[54] Hence, while defendants do not have equal access to special measures in both countries, defendants in England have limited access to intermediaries while defendant in Ireland don't.

Furthermore, there are differences in definition and application of the role of an intermediary in England and Ireland. In England, the role of an intermediary is a profession which is undertaken by different kinds communication specialists.[55] However, while this role was originally only undertaken by professionals with state training on the role of an intermediary and accreditation, professionals without the state training and accreditation sometimes act as intermediaries in cases involving defendants due to the lack of adequate provision for them to gain access to the services of the former.[56] In Ireland, however, there is no clarity on who should fulfil the role and how.[57] As a result, family members, friends and advocates serve as intermediaries in Ireland[58] on an 'ad hoc' basis.[59]

Finally, legal professionals in England tend to have a more favourable attitude towards special measures than legal professionals in Ireland. In England, there has been progress towards the implementation of most special measures, including the use of intermediaries. Additionally, while s 104 of the Coroners and Justice Act 2009 is not yet in force, judges rely on judicial powers allow defendants access to intermediaries. In Ireland, legal professionals

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[51] Samantha Fairclough, ''It doesn't happen…. and I've never thought it was necessary for it to happen': Barriers to vulnerable defendants giving evidence by live link in Crown Court trials' (2017) 21(3) International Journal of Evidence & Proof 209.

[52] Abenaa Owusu-Bempah, 'Understanding the barriers to defendant participation in criminal proceedings in England and Wales' (2020) Legal Studies (Forthcoming).

[53] Alan Cusack, 'Victims of crime with intellectual disabilities and Ireland's adversarial trial: some ontological, procedural and attitudinal concerns' (2017) 68(4) Northern Ireland Legal Quarterly 433; Alan Cusack, 'Addressing vulnerability in Ireland's criminal justice system a survey of recent statutory developments' (2020) International Journal of Evidence & Proof 1 (Forthcoming).

[54] Catherine O'Leary and Michael Feely. 'Alignment of the Irish legal system and Article 13.1 of the CRPD for witnesses with communication difficulties' (2018) 38(1) Disability Studies Quarterly.

[55] Joyce Plotnikoff and Richard Woolfson, 'The 'Go-Between': evaluation of intermediary pathfinder projects' (Office for Criminal Justice Reform 2007).

[56] 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 4.

[57] See Rape Crisis Network Ireland (2018: 10).

[58] Claire Edwards, Gillian Harold and Shane Kilcommins, 'Access to Justice for People with Disabilities as Victims of Crime in Ireland' (National Disability Authority 2012) 113.

[59] Law Reform Commission, *Sexual offences and capacity to consent* (Law Reform Commission 2013) 108.

are reluctant to implement special measures.[60] Consequently, an intermediary was first used in court in 2015[61] due to and fears of the intermediary influencing the witness's response.[62] Due to their lack of enthusiasm for special measures, some legal practitioners and members of the judiciary in Ireland are unaware of the procedural issues involved in granting accommodations under the Criminal Evidence Act 1992. [63] This may result in the misinterpretation of the provisions and subsequent denial of special measures to witnesses who require them as in *D O'D v DPP and Judge Patricia Ryan.*[64]

Conclusion

This chapter has highlighted that there are several support providers who can ensure that people with pychosocial and intellectual disabilities able to communicate in court and understand what is happening during court proceedings in England and Ireland. This chapter has also highlighted similarities and differences in the extent to which this support is provided in the two countries. Legislation in both countries categorise people who require procedural accommodations as vulnerable witnesses, uses pathologising terminology to refer to categories of disabled people which include those who are the focus of this chapter and deny defendants equal access to procedural accommodations. Furthermore, the definition and application of the role of an intermediary and legal professionals' attitudes to special measures are not the same in England and Ireland.

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[60] Alan Cusack, 'Victims of crime with intellectual disabilities and Ireland's adversarial trial: some ontological, procedural and attitudinal concerns' (2017) 68(4) Northern Ireland Legal Quarterly 433; Alan Cusack, 'Addressing vulnerability in Ireland's criminal justice system a survey of recent statutory developments' (2020) International Journal of Evidence & Proof 1 (Forthcoming).

[61] DPP v FE [2015] unreported, (Hunt J) (Bill No. 84/2013 Central Criminal Court).

[62] Claire Edwards, Gillian Harold and Shane Kilcommins, 'Access to Justice for People with Disabilities as Victims of Crime in Ireland' (National Disability Authority 2012) 113.

[63] Alan Cusack, 'Victims of crime with intellectual disabilities and Ireland's adversarial trial: some ontological, procedural and attitudinal concerns' (2017) 68(4) Northern Ireland Legal Quarterly 433.

[64] [2009] IEHC 559.

9 Inclusion and active participation of persons with disabilities in development programs - initial literature review

Jorge Manhique

Abstract

This chapter reviews the literature on disability and development. The objective is to provide an understanding of the state of the art in regard to inclusion and participation of persons with disabilities in development programs - what and how has been studied and which issues are yet to be explored and understood. This review is based on peer reviewed articles, book chapters as well as grey literature (reports from OPDs and INGOs). Peer reviewed articles were identified from online databases using combination of multiple words such as disability, inclusion, participation and development, and through examination of bibliographies of articles and reports. The studies were assessed to find out which aspect of disability inclusion in development programs they address; the theoretical approach and methodological options as well as results and areas that need further consideration. The result of this review suggest that existing studies apply competing theoretical approaches to study inclusion and participation of person with disabilities in development programs, often in social areas such as education. Persons with disabilities are increasingly included in development programs, although additional research is needed to identify the conditions that determine that specific groups of persons with disabilities (e.g. men with physical disabilities) participate in public deliberation and others (eg. women with deaf blindness) don't. Another important area is related with persons with disabilities that are not formally organized and what can be done to encourage and support their participation in development programs as to ensure 'no one is left behind'.

Introduction

There are several areas in which sovereign States usually cooperate.[1] Two are particularly relevant in the context of disability and development - humanitarian and development aid cooperation. They follow different logics although there might be complementarity, and recently have been calls to merge both, by including aspects of prevention in development aid and elements of development in humanitarian aid.[2] This literature review is about inclusion and participation of persons with disabilities in international development aid. The first part review research on inclusion of disability and persons with disabilities in development programs focusing on how those studies have been carried out, the theoretical perspectives used, results and limitation. The second part present the conclusion, which highlights gaps in current literature and emerging research topics.

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[1] International cooperation encompasses a range of areas such peace operations, international security, humanitarian responses and development cooperation.

[2] For more thorough discussion about these two modalities of international cooperation see Hinds (2015).

Theoretical underpinnings

With the adoption of the CRPD in 2006, the discourse on disability and development increasingly focused on the need to merge development, disability and human rights - what is known as Human Rights Based Approach (HRBA) to disability and development. The concept of HRBA to development is not new nor is it specific to disability and can be broadly understood as a process where development and human rights merge and become 'conceptually and operationally inseparable parts of the same processes of social change' (Uvin, 2004. p.175). There are two implications that result from the adoption of the HRBA to development. The first is that the 'goal' of development work changes, as it focuses on claims and not charity. By shifting the focus to claims, the development process is 'deeply political' and not technical or legal (Uvin, 2004, pp. 176). Secondly, HRBA also changes the way development programs are implemented (the process). In this sense, development agencies have to look inward too and conform their processes with human rights standards. This includes equality and non-discrimination, meaningful participation of groups that will be affected by those programs, increased accountability and put in place redress mechanisms (OHCHR, 2012). These principles are all aligned with State obligations under the CRPD (Article 4 and expanded in the General Comment 7).

In part because of the enthusiasm of the paradigm shift brought by the CRPD – from the medical to the human rights model of disability - studies on disability inclusive development have consistently use HRBA to disability as theoretical framework, apolitically and with limited critical engagement (Katsui, 2008). Limited attention is given to the fact that the praxis of disability and development is primary political (Uvin, 2014). Participation, therefore, is usually seen from an instrumental perspective: as mechanism to increase the efficiency of programmes and secure sustainability by engaging local communities (Cornwall, 2008; Frediani, Clark, & Biggeri, 2019). However, these approaches often reproduce processes of exploitation and perpetuation of injustices and miss the real potential of participation in development which is to enable a 'personal, collective and structural process of empowerment' (Frediani, et al. 2019, p. 5).

On the other hand, a more critical approach to disability and development emerged. Stone (1999) and Grech (2009), for instance, have challenge the strategy of 'simply package and export disability and development discourse, theory and models' from the north to the majority world, stating that such strategy have focused only on negative aspects of culture and fails to acknowledge, contextual complexities, differences, local perspectives, histories and other localized forms of support for persons with disabilities. They also criticized the HRBA to development, as western centred (Grech, 2009; Meekosha, 2011). As such, the export of these ideas to the majority world represents 'new form of colonialism' (Bezzina, 2019; Grech, 2009; Meekosha, 2011). The authors call for a 'grounded realism' in the study and practice of disability and development, one which gives priority to 'socio-cultural, political, historical and economic nuances of different contexts' (Grech, 2009). In the same vein, Bezzina makes a call for disability studies to be informed by 'postcolonial theory and to move this into practice by engaging with disabled people's voices, without which inclusive development cannot fully take place '(Bezzina, 2019, p. 433). This calls for new epistemological position in the production of knowledge about disability and development, one which articulates established epistemologies including the 'universal' standards of human rights in dialogue with local ways of staying and being, history and the whole contextual environment (Stone, 1999; Ife and Toscan, 2016). These criticisms are aligned with recent calls for Disability Studies to be 'self-critical, reflexive' and inclusive of persons with disabilities in the majority world (see Goodley, 2017; Meekosha, 2011).

Practical challenges in participation

Previous research on disability and development focused on policy aspects – using the HRBA to development – to examine whether 'persons with disabilities' or the term 'disability' is included in major bilateral and multilateral development agencies policies. Those studies have found that disability is increasingly becoming part of international cooperation (Lord et al. 2010), although in practice, persons with disabilities are not yet benefiting from outcomes of development projects (Groce, et all. 2018) resulting in disparities between those with disabilities and without disability - a phenomenon called 'disability and development gap' (Groce and Kett, 2013).

Development agencies often combine several approaches to address disability, which include human rights, participation, inclusion and development. Disability issues were included both through specific/ targeted and mainstreaming programs (Lord et al. 2010; Keogh, 2014). Yet, this increasing attention to disability at policy level, contrasts with lack of structure and mechanisms to ensure meaningful participation. A recent study which sought to assess EU contribution to the promotion of the rights of persons with disabilities in development cooperation programs and projects across four countries: Paraguay, Sudan and Ethiopia, found that in general there is absence of organized processes, mechanisms and support to enable persons with disabilities to participate across key phases of the project cycle. The study, which used interviews to gather the perspective of EU officials, and review calls for proposals and granted projects, also found that development practitioners lack knowledge on the rights of persons with disabilities or disability inclusive development as well as guidance and good practice on disability inclusion which they could learn from. While staff reported willingness to learn, they also cautioned that disability inclusion must not be a burden for development practitioners (Axelsson, 2019).

Previous research has also focused on the extent to which persons with disabilities through their representative organizations participate in decision making process. A recent global study commissioned by the International Disability Alliance (IDA), the first of its kind, sought to assess OPDs 'perceptions of the quality, depth, scope and relevance of their participation' in legal and regulatory frameworks, policies and strategies, programs and projects led by governments, UN agencies and funding agencies. The study, which used an online based questionnaire, found that persons with disabilities are yet to be fully included in the design and implementation of development programs and policies (IDA, 2019). While progress has been made over the past few years (Keogh, 2016; IDA, 2019) the participation of persons with disabilities in development programs tends to be limited to disability specific issues and social issues [i.e. rehabilitation, training and vocational education] (Ortali, et al. 2013; IDA, 2019) and it is only inclusive of specific categories of disabilities, mainly persons with physical disabilities, visual impairments, usually male. OPDs tend to engage more with Government agencies and UN agencies and little with funding agencies (IDA, 2019). While this study is significant in establishing the baseline and providing empirical data and evidence of OPDs participation at the global scale, the fact that the study was done in the context of the State obligation under the CRPD did not explore how OPDs understand issues of participation in the first place, and how their perspective relates with State obligation under the CRPD article 4.3. Also, while the study identifies the groups who participate and those who are left behind, falls short of fully grasp the conditions under which persons with specific impairment are likely to participate and others excluded from decision making process.

Under international law, the obligation to include persons with disabilities in the decision-making process, and other decisions that affect their lives rests, primarily, with States. A recent study done under the Bridge the Gap Project[3] which sought to assess the effectiveness of participation of OPDs in national government programs, in four low and middle income countries of Africa (Sudan and Ethiopia); and Latin America (Ecuador and Paraguay) found that the level and quality of OPDs participation in national governments decision making processes is perceived by stakeholders interviewed (OPDs representatives, Government Officials) as low in most countries and far from being qualified as meaningful (Cote, 2020). The study identified different degrees of participation in all target countries influenced among others by a complex net of elements which range from unfriendly legal frameworks, difficulties in coordination between Government agencies, lack of transparency and trust in public institution as well as inaccessibility of information to the non-recognition of persons with disabilities as expert on their lived experience and the continued dominance of non-disabled people such as service providers in determining what is supposed to be good for person with disabilities (Cote, 2020). Importantly, the study has developed, based on the CRPD Committee General Comment 7, a framework and a set of indicators to assess the participation of persons with disabilities, which permits some kind of comparison among different countries. However, these indicators were primarily developed to assess the inclusion of OPDs at national level, that is participation in government programs (CRPD article 4) and need further work to be useful in the context of international cooperation.

Knowledge on disability which is very important to the realization of this new paradigm of disability inclusive development, is still absent in many INGO. A recent study, which used an online questionnaire and follow up interviews with officials working for INGOs in the majority world to assess their knowledge and implementation of disability inclusive development policies and practices, found that there is a general lack of awareness of disability (Niewohner, Pierson, Stephen, Meyers, 2019). Some INGOs even claimed that 'there are no persons with disabilities in places where they work'. In addition, the study pointed that there is ignorance or lack of understanding of international norms such as the CRPD or the disability aspects of the SDGs and how that relates to their work (Niewohner et al. 2019). Furthermore, there is an assumption that disability inclusion is expensive, despite evidence suggesting otherwise (Banks and Polack 2014).

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[3] Bridge the Gap Project it's an EU funded project aimed at 'increasing the inclusion of persons with disabilities at both the international and country level'. For more info: https://bridgingthegap-project.eu/about-the-project/

Critical is also the context in which OPDs operate and development programs and projects are implemented, which is characterized by 'weak governance and rule of law, faltering political will, resource and capacity constraints; lack of coordination between different government ministries and between central government and local authorities in implementing disability policies' (WFD, 2019, pp 37). Disability issues are often seen as 'business of the line ministry' despite the constant invocations of disability as a cross-cutting issue (WFD, 2019; Dube 2020). These challenges are usually presented as obstacles to effective mainstreaming of disability in programming (Dube, 2020), however, researchers fail to recognize that this is the reason why these countries are in need of development programs in the first place. Most of the challenges pointed out are common to State building processes, a prevalent reality in the majority world. State building is defined as 'an endogenous process to develop capacity, institutions and legitimacy of the State, driven by state-society relationships' (OCDE, 2008).

Ownership of development programs and relationship between international and domestic actors

One of the main guiding principles in international cooperation is ownership of development programs (Cotonou Agreement, 2000). However, in practice international cooperation can produce perverse results. For instance, studies that assessed the participation of persons with disabilities in national Poverty Reduction Strategy Papers (PRSP) suggest that their involvement was limited, and in general they remained invisible. While in theory the PRSP process aimed to enhance ownership participation and accountability, its design and implementation suggest that Governments were more preoccupied to satisfy donor conditionalities and deadlines than genuinely committed to meaningful involvement and accountability toward its citizens (Dube, 2005; Mwenda, 2009), turning institutions such as the Parliament useless, and contributing to democratic deficit (Macamo, 2006). Conversely, development agencies can leverage their influence to establish bridges between civil society organizations more broadly and recipient Government. Experiences with the PRSP process in Vietnam show examples of development agencies acting as facilitators and bringing together Government and local civil society organization to work together (Fritz, Miller, Gude, Pruisken and Rischewski, 2009). As such, it is important to question the very nature of international cooperation, and openly discuss the type of cooperation and conditions that support the flourishing of democratic culture and sustainability of OPDs. Critically, it is important to bear in mind the limitation of international cooperation as instrument to achieve change, because recipient countries have their own sovereign identity, 'that is they make their own laws and policies' (Keogh, 2017, p. 229).

The CRPD places a specific obligation on State parties to 'closely consult with and actively involve persons with disabilities, including children with disabilities through their representative organizations' (CRPD Article 4 para 3). In this vein, researchers have examined the nature of OPDs in the majority world, their motivations and capacity. Bezzina (2019) based on research carried out in Burkina Faso, found that OPDs face governance challenges and crises of legitimacy. The study, whose findings were obtained through interviews conducted with people with disabilities, INGOs working with people with disabilities and State authorities, revealed that the disability movement is heavily dependent on external funding. While the multiplication of OPDs in most instances arises as a reflection of the diversity that characterizes disabled persons and the complex problems they face

(WFD, 2019), it is also linked with the surge of INGOs who need local partners to implement projects. So, the origin, survival and decay of OPDs is linked to their financial dependency from INGOs (Bezzina, 2019). On a positive note, OPDs in the majority world also represent a source of identification, socialization and solidarity for people with disabilities who usually grow up isolated from the wider society (Bezzina, 2019; Young, et all. 2016). While CRPD article 4.3 calls for the participation of disabled people through their representative organizations, 'it is not the Convention's intent to distance disabled people themselves from participation in decision-making processes' (Löve, Traustadóttir, Rice 2019, p.5). As such, an area which needs further attention is related with groups of persons with disabilities which are not formally organized and may face difficulties to articulate and demand that their concerns are taken into account in public deliberation.

INGOs are key players in international cooperation. According to a recent published report, 35% of disability inclusive development aid is delivered through INGOs (Development Initiatives, 2020). Because of this, INGOs often act as gatekeepers and play a critical role in defining priorities that shape international development programs and projects. Over the past recent years, partially due to demand from donors and the entering into force of the CRPD, INGOs have slowly shifted to embrace the social model of disability and move away from focusing on specific disabilities to work across the disability spectrum (Yoshida, 2009). INGOs have evolved toward seeing disability in the context of the 'overall social and economic development agenda' (Yoshida, at al. 2009, p. 681). This shift also meant that INGOs were required to develop new competences and partnerships (Yoshida, at all. 2009). As such, the new partners needed to be those who speak the same language and have relevant competences usually urban based organizations (Bezzina, 2019). In practice, this defines those who get to participate in public deliberations, and those who do not have that opportunity.

Conclusion

Four main issues emerge from this review. First, while disability is starting to be considered as development issue, it is yet to be systematically mainstreamed in international development cooperation. Second, from a theoretical perspective, existing research apply competing theories to understand the relationship between disability and development in the majority world. However, a more systematic approach - that relates local realities and the voices of persons with disabilities in the majority world with human rights standards – is yet to be developed. Third, previous research has examined the inclusion and participation of persons with disabilities through their representative organizations. While these studies acknowledge that specific groups are left behind, we know little about the circumstances that determine that specific organized groups of persons with disabilities participate in public deliberation and exclusion of others. We also know little about persons with disabilities that are not formally organized and what can be done to encourage and support their participation. Finally, reviewed studies also point out to the need for future research to probe the nature of international development, specifically whether contributes to strengthen local institutions and processes or to undermine them.

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10 'New Legal Realism: a promising legal theory for interdisciplinary and empirical disability-research'

Adriana Caballero-Pérez[1]

> *'The problem is not simply to know what a rule means, but how it lives and works, how it adapts itself to different relations of life, how it is being circumvented and how it succeeds in frustrating circumvention.'*
>
> *Eugen Ehrlich (1917)*[2]

Abstract

New Legal Realism (NLR) is a relevant theoretical strand advancing a constructive relationship between law and the social sciences. NLR broadens the 'scene' in legal studies by placing legal issues in their broader social contexts and follows the aspiration of the scientific study of law. Based on the literature review, this chapter presents a brief discussion on NLR. It finds that four main characteristics of NLR, mainly its law-centred, interdisciplinary, empirical, and constructive legal action character yields useful results to analyse states' compliance with the UN Convention on the Rights of Persons with Disabilities (CRPD). An NLR approach contributes to exploring not only the CRPD implementation into national law but also the social context within which the CRPD operates. In other words, to investigate the 'CRPD-in-action'. The underlying purpose of this chapter is thus to call for collaborative action among legal and social scientific rights defenders by considering to adopt novel theories, such as NLR, to mix normative legal analysis with consideration of broader and holistic perspectives on the disability and human rights.

Introduction

This document departs from the idea that in legal studies, the method to obtain and analyse research material depends on the theoretical approach and, most importantly, on the concept of law accepted in the research.[3] In other words, the concept of (international) law adopted in

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[2] Eugen Ehrlich, 'Judicial Freedom of Decision: Its Principles and Objects' in Ernest Bruncken and Layton Register (translators), *Science of Legal Method. Select Essays by varios authors* (The Boston Book Company 1917) 78.

[3] Professor Hage argues that the method for a branch of science depends on what one takes science to be, on the object of the science in question, on the questions that one asks about this object, on the view one takes on how answers with regard to such questions can be found. The author claims that the proper method for legal science depends on what one takes to be the nature of science, the nature of the law and the kind of questions that are addressed in legal science. See Jaap Hage, 'The Method of a Truly Normative Legal Science' in Mark Van Hoecke (ed), *Methodologies Of Legal Research: Which Kind of Method for What Kind Discipline?* (UK Ed, European Academy of Legal Theory Series Hart Publishing 2013).

a legal study inspires its theoretical approach, which guides the process of planning, collecting and exploring the research material. From this starting point, the purpose of this document is to suggest that a promising legal theory called the 'New Legal Realist approach', inspired by a 'realistic concept of law', might yield useful results in studies of states' compliance with the CRPD since it favours interdisciplinary and empirical research to adequately assess the impact of human rights law, mainly the UN Convention on the Rights of Persons with Disabilities (CRPD).

To achieve this purpose, this paper is divided into four sections. The first section discusses the meaning of the 'realistic concept of law'. This include a brief overview of common perceptions about law and a commentary to understand how human rights law might benefit from a richer exchange between jurisprudential approaches and social sciences theory and methods. The second section deals with the legal theory of New Legal Realism without intending to do so exhaustively. This includes a synthesis of New Leal Realism's distinctive features and a brief historical background of the theory. The third section of this document discusses some of the New Legal Realism's main promises for studies of states' compliance with the CRPD: its interdisciplinary, empirical, and pragmatist dimensions. Lastly, the fourth section of this document includes a concluding remark.

What is a 'realistic concept of law'?

In a doctrinal understanding, law is a comprehensive and rigorously structured science that does not need to resort to any social goals or methods because it is strictly independent. Nevertheless, Realists assert that doctrine is radically indeterminate, therefore, to equate law with doctrine might result in inaccuracies.[4] The main argument of Realists is that, in some cases, the existence of doctrinally predictable results does not imply the existence of any causal or necessary relationship between legal doctrine and the results of concrete cases in a logical or empirical sense. The Realists' claim of legal indeterminacy is understood as a declaration that doctrine can never be an adequate explanation of legal results.[5] The consideration of the motivations of decision makers and the influence that underlying social and political structures have over legal results is at the core of the idea on the inadequacy of doctrinal explanation.

The indeterminacy of doctrinal legal materials, according to H. Dagan and R. Kreitner,[6] requires understanding law as a dynamic set of institutions dealing with tensions between multiple factors, such as power and reason, science and craft, and tradition and progress. This is the 'realistic concept of law.'[7] Viewed in that light, law is neither conceived only as the doctrinal formulations contained in doctrinal materials nor is it only about interest or power

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[4] Ehrlich (n 2); Charles M Yablon, 'The Indeterminacy of the Law: Critical Legal Studies and the Problem of Legal Explanation' (1985) 6 Cardozo Law Review 917.

[5] Morton Horwitz, *The Transformation of American Law, 1870-1960: The Crisis of Legal Orthodoxy* (Harvard University Press 1992); Paul Carrington, 'Hail! Langdell!' (1995) 20 Law & Society Inquiry 691.

[6] Hanoch Dagan and Roy Kreitner, 'The New Legal Realism and The Realist View of Law' (2018) 43 Law & Society Inquiry 528.

[7] For a comprehensive explanation of the 'realistic concept of law' see Stewart Macaulay, 'New Legal Realism: Unpacking a Proposed Definition' (2016) 6 UC Irvine Law Review 149; Dagan and Kreitner (n 6).

politics. Law is an exercise in reason-giving with inherent dynamism.[8] This dynamic conception of law emerges from seeing the law as the product of society that is in a permanently evolving process with changes in society.[9]

As such, law is always in flux as it responds to a changing world and can be used for projects of social change because of its dynamic character. In other words, law is not 'done', and its operation and meaning are shaped by experience. Accordingly, legal studies could adopt a 'realistic concept of law', which refers to law as a social process in 'holistic' terms (or as 'a going institution' as called by Karl Llewellyn).[10] A 'holistic' concept of (international) law includes legal particularities as the set of legally binding rules and principles applicable to the subjects of (international) law, as well as information about the social context and factual environment in which legal mechanisms operate.[11]

It is precisely under this 'holistic' approach to law that it is possible to understand how legal actors use new social developments as 'triggers' for ongoing improvement of the law.[12] Indeed, there are 'paradigm shifts' that confirm how law is a social process embedded in the social sciences and humanities. For instance, the UN CRPD set a 'paradigm shift' for disability by moving towards inclusion of rights holders, using a social model and a disability-human rights framework that understands disability as a human rights issue.[13] These changes in the law about disability are possible because international law is created and used instrumentally. It plays a role in economic, legal, and cultural globalisation processes through catalysing, stabilising, or destabilising.[14]

The role played by law is not only that of being an 'instrument of power', but also a set of particular epistemologies, forms of reason-giving, and communicative practices that contribute to societal development.[15] The practical reasoning is central to international law and there is a social context in which law operates. Therefore, as discussed below, legal studies should combine normative analyses with insights derived from social sciences to develop a 'realistic' sense of how international law is applied in a reality that is also dynamic.

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[8] Dagan and Kreitner (n 6).

[9] Elizabeth Mertz, 'Introduction New Legal Realism: Law and Social Science in the New Millennium' in Elizabeth Mertz, Stewart Macaulay and Thomas W.Mitchel (eds), *The New Legal Realism: Translating Law-and-Society for Today's Legal Practice* (Cambridge University Press 2016).

[10] Karl Llewellyn, 'My Philosophy of Law' in Fred Rothman (ed), *Philosophy of Law: Credos of Sixteen American Scholars* (1941).

[11] Benedict Kingsbury, 'The Concept of "Law" in Global Administrative Law', 20 EJIL (2009) 23; Duncan Kennedy, 'Form and Substance in Private Law Adjudication' 89 Harvard Law Review (1976) 1685.

[12] Dagan and Kreitner (n 6).

[13] See Gerard Quinn and Theresia Degener, 'The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability' (2002); Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 Human Rights Law Review 1.

[14] Gregory Shaffer affirms that international law is constituted by both power and reason (or practical legal reasoning). He argues that international law cannot be understood outside of politics, but that it might be also an error to reduce it to politics. Gregory Shaffer, 'The New Legal Realist Approach to International Law' (2015) 28 Leiden Journal of International Law 189.

[15] ibid.

A commentary on the 'realistic concept' of international human rights law

In today's dynamic world, the new context in which international law interacts is a transnational one. International law is part of the transnational legal ordering of social problems, and these problems can be investigated across levels of social organisation and across different domains of law.[16] For achieving a fully developed human rights legal scholarship, Alexandra Huneeus proposes that legal studies need to combine the perspectives of jurisprudence and social sciences.[17] For the author, strengthening the study of transnational legal phenomena through theoretically informed empirical study makes human rights legal scholarship more useful and productive.[18] This means that it is necessary to understand that studies of compliance with international law can adopt multiple perspectives and that more effective legal reforms are attainable through empirical observation of reality.

One legal theory inspired in the above-explained 'realistic concept of law' that promotes a richer exchange between jurisprudential approaches and social science theory and methods is New Legal Realism (henceforth NLR).[19] The next section discusses NLR as a school of thought with increasing acceptance as a relevant theoretical approach to advance a constructive relationship between law and the social sciences.

What is New Legal Realism?

NLR is a specific legal epistemology encompassing how law obtains meaning, is practised, and changes over time.[20] This approach contributes insights to legal studies from both empirical research and social science theory. Elizabeth Mertz refers to NLR as a 'big tent' perspective to transcend limitations on knowledge.[21] The author asserts 'New Legal Realist work offers the possibility of an integrative effort that reaches not only across disciplines but across people and legal systems.'[22] This kind of legal epistemology might challenge the adequacy of studying the legal system when that concept is defined formally and narrowly owing to the fact that reality is naturally changing and 'messy' as explained by Stewart Macaulay.[23] In this sense, an NLR approach broadens the 'scene'; it places legal issues in their broader social contexts and follows the 'aspiration' of the scientific study of law.

As a legal theory, the main concern of NLR is to discover the meaning of law based on its impact at the point of delivery.[24] In so doing, NLR takes doctrine seriously and move from law in books to investigate law-in-action.[25] It is a legal scholarship that understands that

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[16] ibid.

[17] Alexandra Huneeus, 'Human Rights between Jurisprudence and Social Science' (2015) 28 Leiden Journal of International Law 255.

[18] ibid.

[19] Bryant Garth and Elizabeth Mertz, 'Introduction: New Legal Realism at Ten Years and Beyond' (2016) 6 UC Irvine Law Review 122.

[20] Shaffer (n 14).

[21] Mertz (n 9), 22-27.

[22] ibid, 22.

[23] Stewart Macaulay, 'The New versus The Old Legal Realism: "Things Ain't What They Used to Be"' (2005) 2005 Wisconsin Law Review 365.

[24] See Macaulay (n 7).

[25] *'Law-in-action'* and '*living-law*' are two terms that arose from the Legal Realism approach. They both correspond to the notion of how law works or operates on the ground. The idea of '*the law in action*' comes from Professor Roscoe Pound. According to R. Pound, '*law-in-*

doctrine and legal processes play a role to elucidate legal outcomes (i.e., NLR is law-centred).[26] Additionally, NLR recognises that the impact of law depends on different factors, such as discretion of actors, social practices, political influence, and multiple issues influencing how law manifests once it reaches the lives of people. By identifying those issues, a study underpinned in an NLR approach, contributes to make social systems be aware of those issues to solve them (i.e., NLR is committed to constructive legal action). NLR also seeks to create a genuinely interdisciplinary form of legal knowledge based on the particularities of the epistemological and normative questions at issue, namely problems that emanate from legal practice (i.e., NLR favours interdisciplinarity in the study of law). Furthermore, NLR scholars focus on the relation between law to social order and social change using a 'bottom-up' approach (i.e., NLR is oriented bottom-up) in addition to 'top-down' approaches in studying law because the central concern is the local delivery of law on the ground.[27]

In legal studies, the purpose of incorporating an NLR approach is to recognise that at the point of delivery, law impacts beyond lawmaker intentions. The focus on 'the impact' of the law was also shared by the original legal Realists, who were concerned with studying the consequences of legal rules in society, as explained in the next section. Nevertheless, NLR extends the original legal Realists' vision and embrace the wide range of social sciences' theories, epistemologies, and 'facts' to study the delivery of law on the ground.[28]

Brief historical background of the New Legal Realism

Historically, the term 'Legal Realism' was associated with the idea that judges ignore the law and make case decisions at their discretion.[29] However, Legal Realism does not necessarily deny a role for the law in the judicial decision-making process.[30] Realism simply means that judicial decisions are not based on 'formalistic law,' acknowledging the various factors influencing courts. Frank B. Cross affirms that the Realists certainly had it right in the claim

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action' focuses on the gap between the law in the books and the actual practices of legal officials and the public in cases of disputes. The idea of '*living law*' corresponds to Eugene Ehrlich and refers mainly to the norms recognized as obligatory by citizens in their capacity as members of associations. This document is conceived very much in the R. Pound tradition of studies of legal effectiveness. Thus, this document uses the phrase '*law-in-action*.' See Roscoe Pound, 'The Scope and Purpose of Sociological Jurisprudence' (1911) 24 Harvard Law Review 591. In Brian Z Tamanaha, 'The Third Pillar of Jurisprudence: Social Legal Theory' (2014) 56 William & Mary Law Review 2235, 2238. ; Eugen Ehrlich, *Fundamental Principles of the Sociology of Law* (4th edn, Transaction Publishers, New Brunswick and London 2009).

[26] Doctrine is the 'key language' through which law works. E. Mertz affirms that doctrine is the *backbone* that supports the delivery of law on the ground, but it does not offer the most accurate possible picture of how law actually operates in everyday life. See Ino Augsberg, 'Some Realism About New Legal Realism: What's New, What's Legal, What's Real?' (2015) 28 Leiden Journal of International Law 457.; Mertz (n 9).

[27] As expressed by B. Garth and E. Mertz '*the concept of 'bottom-up' includes both methods that start from the ground level of law as it works in action –in actual social life- and also perspectives on law drawn from the study of non-elite members of a social hierarchy*.' See Garth and Mertz (n 19). 125, footnote 15.

[28] There are two historical strands of NLR: Scandinavian and American approaches. For a comprehensive explanation of both NLR's strands see Gregory S Alexander, 'Comparing the Two Legal Realisms American and Scandinavian' (2002) 50 The American Journal of Comparative Law 131.

[29] The beginning of Legal Realism is chronologically situated in the 1920s and 1930s.

[30] Frank B Cross, 'The New Legal Realism and Statutory Interpretation' (2013) 1 The Theory and Practice of Legislation 129.

that judicial decisions are not 'some algorithmic application of legal materials.'[31] The author claims that judicial decisions, as expressed by the original legal Realists, are influenced by extra-legal circumstances, and what Legal Realism does is to recognise those circumstances looking for answers to questions such as what are those extra-legal factors? When do they apply? Additionally, how can they be shaped to produce more desirable results? The original legal Realists suggested that decisions could be explained by those factors.[32]

The legacy of the Old Legal Realists was to promote changes in the mind of legal scholars and lawyers to think about how social context influences the delivery of law, mainly how certain real-world influences, outside the realm of doctrine, affect judges' decision making. Consistent with this view, Karl Llewellyn,[33] one of the original Realists, called Realism 'a technology.' He claimed that Realism was nothing more than a 'good method' and used ethnography as the primary 'technology' in his legal studies.[34] To summarise, Realism aimed to describe how judges decide and the key focus of most of the original Realists was appellate judging. The historical relevance of the Old Legal Realism originates from its discredit of formal approaches.[35]

From the novel approach to study law set by Old Realists scholars, in the early 1950s NLR arose addressing questions asked within what Brian Tamanaha calls the 'third pillar' of jurisprudence or 'Social Legal Theory.'[36] B. Tamanaha refers to social science approaches to law as a distinct 'third-pillar' of jurisprudence, closer to the so-called 'historical jurisprudence' that takes an empirically oriented angle on law.[37] From the 'third-pillar', law is viewed as a social institution and as instrumental. Such a 'third jurisprudential pillar' emerges as a coherent alternative to natural law (fixed in a moral theorising of law, namely with a normative angle on law) and legal positivism (or analytical jurisprudence with a

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[31] Frank B. Cross argues that the evidence on how judges decide cases is complex and not completely legal. The law does matter but so do numerous extra-legal considerations. See ibid, 147.

[32] From a legal realists perspective, judicial decisions appear to be a product of multiple factors interacting with one another in different ways in different circumstances. The analyses of those factors and their interactions informs the relevance of Legal Realism to statutory interpretation. See Mertz (n 3). Frank B. Cross defines 'statutory interpretation' as a delegated power, where judges are supposed to do the bidding of the legislature. However, the justices are not 'powerless' in response. See Cross (n 30). 144-145

[33] Karl Llewellyn was one of founders of the U.S. Legal Realism movement. He applauded social science informing jurisprudence. See Karl N Llewellyn, 'Some Realism About Realism -Responding to Dean Pound' (1931) 44 Harvard Law Review 1222; Karl N Llewellyn, *The Common Law Tradition: Deciding Apeals* (Little, Brown 1960).

[34] Many years later, Gregory Shaffer also used the term 'technology' to explain law from a pragmatist's point of view. He asserted that legal knowledge arises from engagement with the social world; legal knowledge is developed and used, like a technology, to respond to and resolve problems. Shaffer (n 14).

[35] What is noteworthy about Old Legal Realists is that they pointed to the marginality of law, and suggested that researchers had to look beyond the law and legal rules if they were fully to understand the phenomena they were concerned with. See Macaulay (n 23).

[36] Tamanaha (n 25).

[37] Friedrich Carl von Savigny and Henry Maine are two of the greatest scholars of the historical jurisprudence; their works support a theory of law focused on the connection between law and society. John B Halsted, 'Friedrich von Savigny: Of The Vocation of Our Age for Legislation and Jurisprudence' in John B Halsted (ed), *Romanticism: The Documentary History of Western Civilization* (Palgrave Macmillan 1969). Maine focused his works on legal fictions and the way judges changed law to keep pace with societal changes. See for instance: Stephen Utz, 'Maine's Ancient Law and Legal Theory' (1984) 69 Faculty Articles and Papers. University of Connecticut 821.

conceptual angle on law). B. Tamanaha affirms that these three jurisprudential streams represent genuine theoretical alternatives.[38]

Under the 'third pillar' of jurisprudence, NLR develops an interactive process between theory and practice (empirical research) and focuses not only on courts, as it tended to be in the case for the Old Legal Realism, but also on social actors, and administrative and private parties in a broader view of the social context within which law operates.[39] According to Elizabeth Mertz,[40] the first years of NLR were characterized by a sharp division over methodologies within the group of scholars working to integrate social science into schools of legal thought. Undoubtedly, during its evolving process, NLR sets itself apart from other efforts to integrate social science into law or use empirical findings in legal reviews.[41] In particular, NLR pays attention to epistemology and analytical theory, which makes it different from Empirical Legal Studies or Law and Economics.[42] Furthermore, NLR differentiates itself from Critical Legal Studies by not taking law as an ideology or as structurally indeterminate in principle and adopting a pragmatic problem-solving focus through an empirical methodological approach.[43]

As part of the distinctive character of the NLR, E. Mertz asserts that the New Legal Realist approach adds to the law-and-society tradition a focus on 'translating' between law and social science.[44] E. Mertz calls for accomplishing a 'translation' by considering first the interdisciplinary communication process itself.[45] Accordingly, H. Dagan and R. Kreitner[46]

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[38] In *'The Third Pillar of Jurisprudence',* B. Tamanaha asserts that a third major pillar of jurisprudence has existed for several centuries in opposition to natural law and legal positivism; however, it has been mostly unrecognized, owing to what he calls 'the vagaries of labeling and intellectual fashion.' Tamanaha traces the 'third-pillar' roots back to Montesquieu's *'The Spirit of the Laws'* in which Montesquieu set forth a descriptive account of law as a social institution and as the product of the history of a society, and stressed the relation of law to political, social, and geographical contexts. B. Tamanaha also recalls Roscoe Pound's words on the existence of three legal schools: '*Until recently, it has been possible to divide jurists into three principle groups, according to their views of the nature of law and the standpoint from which the science of law should be approached. We may call these groups the Philosophical School [natural law], the Historical School, and the Analytical School*.' See Pound (n 25). In Brian Z Tamanaha, 'The Third Pillar of Jurisprudence: Social Legal Theory' (2014) 56 William & Mary Law Review 2235, 2238.

[39] See Mertz (n 9).

[40] E. Mertz claims that trained social scientists initially conducted studies of law-in-society but that those studies occupied a marginal place in legal scholarship. She explains that legal scholars were not aware of the connections between law and society. Consequently, legal scholars dismissed other epistemologies and theories. ibid.

[41] B. Garth and E. Mertz affirm that the earlier Legal Realism began the development of the relationship between law and the social sciences. Law reviews from Old Legal Realism worked on law and economics, and behavioural law and economics. The main feature of New Legal Realism is its emphasis on the translation of social sciences theories (including methods and findings from those theories) into mainstream legal scholarship. See, for instance, Garth and Mertz (n 19).

[42] Mertz (n 9).

[43] As Elizabeth Mertz asserts, the Critical Legal Studies movement used forms of social theory, but they did not explore the grounded empirical research programs that social theory proposes. Similarly, Empirical Legal Studies lacked integration since they supported a kind of empiricism without social science theory. See Garth and Mertz (n 19). Furthermore, as suggested by Gregory Shaffer, New Legal Realists contrast with critical legal scholars because the latter do not engage with the empirical study of law for pragmatic decision-making. See Shaffer (n 14).

In fact, according to Jakob Holtermann and Mikael Madsen, Critical Legal Studies tends to reduce law to a mere tool of domination. See Jakob V Holtermann and Mikael Madsen, 'European New Legal Realism and International Law: How to Make International Law Intelligible' (2015) 28 Leiden Journal of International Law 211.

[44] According to Elizabeth Mertz, 'translation' is a 'conversation' between two sets of theories, epistemologies, and 'facts'. See Mertz (n 9).

[45] Regarding the 'translating' between law and social science, H. Dagan and R. Kreitner suggest that 'translating' could not be the best way to describe the tasks of NLR scholars since what they are really pursuing is 'interdisciplinarity'. They affirm 'the endeavor may be

suggest that 'translating' could not be the best term to describe the tasks of NLR scholars since what they are really pursuing is 'interdisciplinarity'. The authors assert that the NLR scholars' endeavour is 'more like a joint engineering project than a translation.'[47] This means that the main task in conducting NLR studies is to look for a way to combine two sets of tools based on a commitment to shifting hierarchies among disciplines (interdisciplinary studies). In other words, NLR is not about taking findings from social science and putting them into legal reviews, but to improve ways to understand the context that gives meaning to the law.

As an evolving legal theory, NLR's main promises and most significant challenges (primarily its interdisciplinary, empirical, and pragmatist dimensions) are discussed in the next section, which suggests that these NLR's dimensions might yield useful results in studies of states' compliance with the CRPD.

Adopting an NLR approach in studies of states' compliance with the CRPD

NLR underpins an analysis of the 'law-in-action' (or the 'CRPD-in-action'), namely, how the Convention is implemented and how persons with disabilities experience it. NLR, as legal theory when analysing compliance with the CRPD contributes to analyse the social context within which the CRPD (as an international human rights treaty) operates. As such, an NLR approach helps to add insights to studies of states' compliance with the CRPD from certain promises: interdisciplinary, empirical research, and a commitment to constructive legal action.

Firstly, NLR promotes interdisciplinarity and empiricism in compliance analyses. In doing so, NLR highlights the relevance of combining attention to both doctrine and social science. It addresses the CRPD as an international human rights legal instrument and the international and domestic legal institutions that play a role in the CRPD implementation. Additionally, NLR recognises that the impact of the CRPD depends on different factors, such as the self-determination or agency of persons with disabilities; actors' understandings of the disability itself and the CRPD norms; practices within social systems; political influences; and multiple other issues affecting how the CRPD works out once it reaches the lives of persons with disabilities. Without embracing the wide range of social sciences' theories, epistemologies, and research methods, it is not possible to offer an accurate picture of how the CRPD is truly implemented. Thus, an NLR approach in analysis of states' compliance demonstrates the power of 'translating' or communicating legal knowledge with other multiple disciplines. In so doing, NLR offers the possibility of an integrative effort in disability-research that reaches not only across disciplines but also across persons with disabilities and even different legal systems.

Secondly, NLR is committed to constructive analysis of states' compliance with law. This is the pragmatist (or problem-centred) dimension of NLR. Viewed in this light, NLR

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more like a joint engineering project than a translation.' This means that the main task in conducting NLR studies is to look for a way to combine two sets of tools based on a commitment to shifting hierarchies among disciplines. See Dagan and Kreitner (n 6). 545

[46] ibid.

[47] ibid, 545.

encourages disability scholars to pursue an action-oriented research purpose with a more pragmatic emphasis. Thus, the motive to adopt an NLR approach in studies of states' compliance with the CRPD is to provide subjects of law with a clear understanding of legal, social, and perhaps cultural issues that influence the CRPD implementation. By pointing out the problems arising from social systems that affect the 'delivery' of the CRPD on the ground (or the CRPD implementation), an NLR approach helps social systems to be aware of such issues to solve them. In doing so, NLR underpins using the study of law to improve the living-conditions of persons with disabilities.

The above-mentioned NLR's promises are interdependent and inspire each other. Such promises might yield useful results to the analysis of compliance with the CRPD since based on a legal theory that favours interdisciplinary and empirical research, and has a pragmatist dimension, researchers might not only interpret the legal obligations of States Parties resulting from the CRPD but also address how States Parties comply with these legal obligations, namely how the CRPD has an effect in domestic laws and policies, and, more importantly, in persons with disabilities' lives. In short, an NLR approach contributes to research 'the CRPD-in-action'.

Conclusion

The 'realistic concept of law' situates law as an exercise in reason-giving that has an inherent dynamism. This concept of law inspires the New Legal Realist scholarship, which has four distinctive features: (i) is law-centred; (ii) is committed to constructive legal action; (iii) favours interdisciplinary and empirical research; and (iv) is oriented bottom-up. The main possibilities of NLR that might yield useful results in studies of states' compliance with the CRPD are its interdisciplinary, empirical methodological approach, and pragmatic-solving focus. These principles assess the impact of human rights law, mainly the CRPD, not only at the legislative or institutional levels, but also in practice, i.e., in the daily lives of persons with disabilities.

This chapter is a call for collaborative action among legal and social scientific rights defenders by considering to adopt novel theories, such as NLR. Further research focusing on the effectiveness, feasibility, and acceptability of applying an NLR approach to the study of states' compliance with international law need to be undertaken to inform research on the disability and human rights.

11 Social movements and civil society: an exploration of possibilities

Claudia Harris Coveney

Abstract

This chapter introduces several conceptions of civil society and their consequences for social movement organisations, specifically disabled people's organisations (DPOs). It first discusses two conceptions that frame the space of civil society as normatively good, before turning to a more critical one. This conception combines Gramscian and Foucauldian thought and looks at the role of civil society in current modes of governance. It frames civil society as a technology of government, used by modern liberal states to 'govern at a distance' and a vital element of hegemonic dominance. The chapter then explores the implications of this perspective for DPOs and their collective action goals and agendas. Civil society enables the governing of domains located outside state structures, shaping the objectives of organisations to align with those of the state. However, DPOs and other movements have successfully utilised the civil society space to influence decision-making at numerous state levels and engage with counterhegemonic practices to correct marginalising social structures. The chapter argues that to assess the opportunities for social movement organisations to pursue their objectives within this space, research looking at interactions between DPOs and government bodies is needed. It then introduces a current research project that examines past collective action campaigns that have targeted EU-level bodies of governance to understand what kinds of tactics and strategies have enabled DPOs to utilise the civil society space and further their agendas. It concludes with a discussion of the project's design according to the emancipatory disability research paradigm.

This chapter will discuss the potential of civil society as a space for social movement organisations to engage as blocs in counterhegemonic practices through collective action. It explores the possibilities of this collective action in relation to social movement and governance scholarship, specifically in the case of the European disabled people's movement (EU DPM). It introduces several questions that address current gaps in knowledge. The primary question is how the EU DPM as a social movement has sought to influence various aspects of EU-level governance.

Defining civil society

According to the Tocquevillian perspective, civil society is generally said to be necessary for a healthy functioning of a democracy (Putnam, 2000; de Tocqueville 2003); a barrier to unwanted state encroachment that includes all voluntary associations. Civil society here acts as a normatively 'good' safeguard on democracy, in itself neutral. Its aim is to restrict state power, but not extinguish it.

Stemming from the thought of Habermas (2015) is another conception of civil society, the 'third sector'. This definition is one favoured by international NGOs, describing civil society as a sphere beyond that of the market or state. According to the World Health Organisation, civil society is 'the space for collective action around shared interests, purposes and values, generally distinct from government and commercial for-profit actors' (WHO, 2020). The United Nations describes it as 'the "third sector" of society, along with government and business. It comprises civil society organizations and non-governmental organizations' (UN, 2020). In the lexicon of the European Union, civil society comprises all 'social action carried out by individuals or groups … neither connected to nor managed by the state' (EU, 2020). This conception depicts civil society simultaneously as free from the exploitative and administrative logics of the market and state and a communicative sphere in which public opinion is shaped and issues shifted onto the political agenda accordingly (Habermas, 2015). Civil society here remains normatively 'good'.

In Gramsci's (1971) conception of hegemony, however, civil society plays a crucial role as the sphere of institutions that are run and supported by people outside of the other two spheres of state and economy. Importantly, it is a space that requires legitimacy from the state for entry. It is not synonymous with all non-business and non-government related collective activity - more precisely, civil society is a space consisting of organisations that have been granted access by the state (Fraser, 1990: 60; Rose & Miller, 2010). It is a formal arena in which 'private' interests can be translated into the public institutions of the state (Melucci, 1996: 219).

Civil society is thus an integral element of the modern liberal state, following this conception, one which rules through 'governmentalisation' (Foucault, quoted in Rose & Miller 2010: 273). This is a network of state and non-state institutions and organisations; an interdependent complex of discursive rationalisation (moral justification) and intellectual machinery (language) deployed through governmental technologies (administrative programmes and procedures) (281). Political power does not constrain citizens; rather it equips them with a certain type of freedom (272; Cruikshank, 1999). Civil society signifies a free space outside the political realm in liberalism. Simultaneously, it is also the task of the state to nurture the self-organising capacity of the space. This is a key element in the 'governing at a distance' approach of the modern state (Rose, 1996; Rose & Miller, 2010).

According to Oliver (1990: 99), service provision from the welfare state has reinforced the construction of the dependent disabled person in an era of dependency reduction; these processes have only accelerated since Oliver's initial diagnosis in his seminal 1990 text, The Politics of Disablement. Participation as citizens in the political system is challenging for disabled people: transport and physical access to polling stations, inaccessibility of constituency headquarters and other physical barriers to grassroots activism all hinder their ability to fully exercise their rights. Structural divisions prevent disabled people from becoming a powerful, politically unified voice – disability runs across many societal cleavages and many do not see their impairment as a defining feature of their identity (see Oliver, 1990: 106; Beckett, 2006). Pressure group activity can be damaging if the group representing the interests of disabled people is run by salaried professionals who transpose their own impressions of the needs of disabled people and assume that disabled people cannot speak for themselves. Inclusion in the political process in such a way accepts the othering of disabled people. It embeds the organization of society that places disabled people at a disadvantage. For Oliver (1990: 135) and others (see for example Priestley, Waddington & Bessozi, 2010) the answer to challenging this construction lies in civil society organisations and their counterhegemonic practices.

Social movements and their potential

Social movements have been touted as vehicles to enact lasting social change in favour of structurally oppressed blocs. In conceptions of 'New Social Movements' (NSMs), they are conceptualised as collectives of people, drawn together to challenge an element of society at a political or cultural level and enact change through this challenge (Melucci, 1996; Touraine, 1981; Oliver, 1990). Importantly, as put by Melucci (1989: 30): '[Their] actions violate the boundaries or tolerance of a system, thereby pushing the system beyond the range of variations it can tolerate without altering its structure.'

In other words, (new) social movements define themselves in counterhegemonic terms. In practice, social movements encompass a vast range of groups and activities, stretching from a radical, subaltern level to a highly institutionalised, bureaucratic one (della Porta & Diani, 1999). The counterhegemonic practices undertaken by these organisations is referred to as 'collective action'. Collective action can be defined as: "[A]n articulated structure of relations, circuits of interactions and influence, choices among alternative forms of behaviour" (Melucci, 1996: 22)

Collective action is a consciously selected set of actions by a representative group that engage in counterhegemonic ideas and practices to further the agenda of a social movement.

Castells (1997: 2) defines social movements as 'purposive collective actions whose outcome, in victory as in defeat, transforms the values and institutions of society'. This definition is useful in capturing the essence of social movements and their power, and demarcates a point where success or failure can be definitively measured that is not often seen in social movement literature. Their consequences manifest in different forms – enduring change can appear even after a movement has not reached its objectives, and this change may not take an institutionalised, legislated form (Suh, 2012; Tarrow, 1998). Often cultural success precedes policy change as an indicator of structural transformation – movement objectives will likely gain a groundswell of legitimising support before they appear at a formal level of governance (Gamson, 1998; Suh, 2012). Movements may find their campaign co-opted if state actors pay lip service to their demands but fail to meaningfully include them in the decision-making process (Gamson, 1990). Suh (2012) points out too that the passing of policies and bills does not always translate to their enactment. The ongoing monitoring and reporting of state parties to the UNCRPD is indicative of this. Much of the EDF's work is monitoring the activities of state governments in protecting the rights of disabled people in their jurisdictions.

The work of DPOs, amongst other social movement organisations (SMOs) in this context provides evidence that civil society does present sites of resistance to hegemony (Jessop, 2002: 8). Extensions of rights to different groups or wide-ranging social change enacted by SMOs have emerged through a process of application of pressure to the state and the garnering of widespread public support (Fraser, 2013). Separate from traditional party politics, this interface - the political dimension of civil society activity - between state actors and non-governmental, non-profit actors is one where ideas can indeed be introduced by organisations representing the interests of specific societal groups to influence policy debates, discourse and direction (Fraser, 1990; Habermas, 2015). In this way, social movements can be seen to break the limits of compatibility with a system and trigger change (Melucci, 1996).

Many of the collective challenges faced today by society are being navigated by complex networks of actors from public, private and societal spheres. This is a departure from direct power exercised by traditional nation state institutions, towards the involvement of market and civil society actors alongside traditional hierarchies (Rhodes, 1996: 652). Sørensen (2006) describes the exercise of sovereign rule by a 'parliamentary chain' of governing making way for a host of stakeholders and private actors who have gained the ability to partake in public decision-making. This can be distinguished from more traditional forms of government in the *ways* that new actors are involved: new public governance incorporates non-state groups into decision making, rather than heeding to the loudest external lobby groups.

These changes have increased opportunities for participation in decision making for a range of groups and changed the policy process. Indeed, most governance networks only involve stakeholders who possess resources critical to the policy 'problem' (Klijn & Koppenjan 2016: 227). However, European institutions have drawn in stakeholder groups through formalised civil society organisations like the European Economic and Social Committee. Additionally, and particularly pertinent to the present research, the EU as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is obligated under Article 4 (3) to involve disabled people in the development of laws and policies that concern them.

This phenomenon challenges a traditional representative democracy model because the sovereignty of rule by elected politicians has been diluted with the addition of new actors with governing abilities. Less 'empowered' or educated citizens are unlikely to utilise these channels of influence as much as actors with pre-existing strong political resources (Sørensen, 2006: 104; Sørensen & Torfing 2005: 216). Concern has been expressed that processes of co-production with citizen groups are touted as panaceas for various social challenges, but outcomes are rarely evaluated (see for example the systematic review of articles and books on co-creation and co-production by Voorberg, Bekkers & Tummers, 2014). This furthers the potential for uneven access to public decision making spaces, not only because new processes might not be easy to use for those who are less experienced and historically marginalised, but these new channels are eroding the capacity of other, more traditional channels of access — local council members, for example, if their voice on behalf of their constituency becomes diluted in the decision making process. Papadopoulos (2012: 523) points out that many actors in a governance network are in fact either partially authorised or completely unauthorised in terms of democratic election. Further to this problem of uneven access, Klijn & Koppenjan admit that although the presence of new actors is increasing in governance networks, '[p]articipating individuals are reported to be atypical, often highly educated, well-to-do, white, male, and unrepresentative of the groups affected by the policy or problem under discussion' (2016: 227). The 'moral justification', or political rationalisation of government demands accountability and transparency in decision making processes (Rose & Miller, 2010; Benz & Papadopoulos, 2006; Wagenaar, 2016), and questions as to how governance networks should be regulated are raised. From the perspective of social movements, these shifts in governing styles offer opportunities and risk. Opening up the decision-making process to a spectrum of actors could mean that collectives, on behalf of a social movement, can ensure their interests are represented by becoming directly involved in negotiation processes, if they are included.

The DARE project's ESR 12 seeks to assess the opportunities presented in recent evolutions of governance for these civil society organisations to engage in counterhegemonic practices. This research will view collective action through the lens of targeted campaigns levelled at formal governance bodies, although not all social movement activity takes this form. It will ask, from the perspective of the actors within the movement, what has been important and what constitutes success. Further, it asks which organisations are given platforms to speak on behalf of a movement. The present research explores the cases of policy that have been made in consultation with DPOs to determine whether the interests of disabled people and their organisations are better met when they are represented in decision-making processes.

The research will be undertaken in close collaboration with the EDF and using a two-way accountability mechanism in the form of a supervisory board. The findings will be generalised to contribute to the body of knowledge around collective action activity (Mason, 2002: 8) and translated into an accessible framework of collective action and disseminated in collaboration with DPOs to maximise their reach. It is important to briefly consider the researcher's role as a nondisabled person working with DPOs, following the principles of emancipatory disability research. Stone & Priestley (1996) outline six core principles of the emancipatory research approach (see also Barnes, 2004). The principles, and the way they are utilised in the present research (italicised), follow:

1. Accountability: Continuous and meaningful input by the disabled community from the design phase to dissemination of research

The topic of the research was designed by the DARE project, which is made up of academic institutions, service provider organisations and DPOs. Contact with the EDF began with my project application and has shaped the project's proposed design and the selection of cases for study. A formal advisory board, consisting of DPO representatives, will inform the next stages of data generation and analysis. The EDF will also play a key role in the dissemination of the research findings.

2. The role of the social model: The epistemological position for the research should be to expose and interrogate the disabling structures of society

The primary aim of the research is to explore how DPOs as SMOs engage with counterhegemonic collective action to disrupt disabling social structures.

3. The question of objectivity: Acknowledging the myth of interpreting data without bias and making clear the position being taken in the research

The resulting collective action framework from this research can be utilised by DPOs to their benefit.

4. The choice of methodology: Ensuring rigor, logic, and clear structure so as to best capture the complex experience of disablement

The research design is informed both by consultation with DPOs and similar past research projects. Methods have been chosen based on their ability to best answer the research questions and checked with the DPO.

5. The place of experience in research: Allowing room for lived, subjective experiences and realities of disabled people in a way that can be collectivised

The project will answer its research questions through accounts of participants representing DPOs that ran targeted campaigns and associated archival material. The approach uses individual accounts of activist experience with collective action.

6. Research outcomes: Ensuring meaningful, practical and accessible results for the disabled community

> *Particular attention is being paid to the dissemination of the research results. Time will be made to consult with DPOs and relevant literature on accessibility. The framework of collective action is one such initiative. The results will also be translated into other language according to the wishes of member organisations that will assist in disseminating the results. I will present the findings in an accessible format to DPOs visually, and verbally, not just in text format. Events held by the EDF and its member DPOs are a platform for these presentations.*

Conclusions will be conceptualised to create a collective action framework that details the characteristics and conditions of social movement activity that strengthens European DPOs from the perspectives of engaging in social and institutional processes of change.

Dissemination of the framework is a crucial step in the research project, and one that will receive ongoing attention. The collective action framework will be circulated in a number of ways to international, state, regional and local-level DPOs. Initial ideas for dissemination have been mentioned in the discussion of emancipatory disability research paradigm – particularly how the research will engage with Principle 6 (Stone & Priestley, 1996).

Other avenues that are being considered for dissemination are events held by the EDF, wider civil society gatherings like the European Economic and Social Committee (EESC), state departments and supranational, national and local levels, UN CRPD committees, and academic settings like conferences.

The project explores meanings of success in social movement activities and governance processes and the opportunities and challenges that DPOs may find in the state-designated civil society space. Findings will contribute to knowledge of how collective action taken by DPOs can further their objectives as a movement. The interdisciplinary grounding of the research will allow a more comprehensive understanding of how governance and social movement organisations can work collaboratively.

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12 Oral history as a methodological approach for researching the activism of women with disabilities

Aoife Price

Abstract

This chapter provides a rationale for using oral history as a methodology for a research project exploring the activism of women with disabilities within the disability and feminist movements. The aims and objectives of the study, as well as some background information, are provided to help the reader establish an understanding of the project. Oral history is defined, and the chapter looks at how it fits well within disability studies and the disabled people's movement as well as briefly looking at its significance in the feminist movement and women's studies. The methodology used in forming the argument on the suitability of using oral history in this piece of writing is gathered through a review of the literature. The implications of this piece of writing is that it provides a good understanding of the bases of oral history and how it fits with my PhD studies as the most appropriate methodology.

Introduction

This chapter explores why oral history is an appropriate method to utilise for this research project exploring the activism of women with disabilities. It will consider the use of oral history as a methodology in the area of disability studies as well as in non-academic settings. A review of the literature reveals that while only a few studies involving persons with disabilities strictly adhered to the oral history as a methodology, there are projects that use other terminologies such as life history, narrative research and storytelling but are very close to oral history in their approach. Throughout the research, I will draw on many of the different ways in which the voices of persons with disabilities is heard. These approaches are all connected in what they reveal about persons with disabilities and their efforts to amplify the voice of persons with disabilities.

Background

Social movements are conscious, concerted, and sustained efforts by ordinary people to change some aspect of their society by using extra-institutional means.(Jeff Goodwin & James M. Jasper, 2014, p. 3) They have essential relevance in politics as they are among the main political forces to influence public opinion, public policies, and regime transformation.(Kateřina Vráblíková, 2017, p. 36) The disability and feminist movement have both involved women with diabilities, however some feel they have not been heard in either. General comment number 3 by the United Nations Committee on the Rights of Persons with Disabilities (CRPD) looks at article 6 focusing on women and girls with disabilities.(Committee on the Rights of Persons with Disabilities, 2016, p. 15) It references the right to participation in political and public life (art. 29) and notes that the voices of women and girls with disabilities have historically been silenced, which is why they are disproportionately underrepresented in public decision-making. Being actively involved in civil society discourse and debate is at the heart of what it means to live in a democracy. The focus of this study will centre around the experience of women with disabilities participation in social movements, specifically in the disability and women's movement. It will draw on their experiences at the European level. Prior to explaining why oral history is a relevant methodology for this research, it is important to set out the research aim and objectives.

Research Aim and Objectives

The study aims to explore the experience of European women with disabilities in the disability and feminist movements.

The objectives of the study are to:

- Explore:
    - The meaning and purpose of activism for women with disabilities.
    - Women with disabilities' experience in both the disability and feminist movements.
    - Women with disabilities' hopes for both movements supporting their involvement in the future.
- Reflect on how both movements can best facilitate and work together to enable the voices of women with disabilities.

Oral History Overview

Oral history is the recording of people's memories, experiences and opinions. (Lynn Abrams, 2016, p. 3) As a methodology, it is used a wide range of scholarly disciplines. It is used not only by academics but also in the wider community, including by activists in a range of social movements. (Lynn Abrams, 2016, p. 3) It has resulted in a vibrant and continually evolving research practice that draws upon innovative findings across a broad spectrum. Portelli explains how oral history is permeable and borderless, a 'composite genre' which requires that we think flexibly, across and between disciplinary boundaries, in order to make the most of this rich and complex source. (Lynn Abrams, 2016, p. 3) Oral history involves communicating with a living, breathing human being. It is a conversation in real-time between the interviewer and the narrator.(Lynn Abrams, 2016, p. 27) Over the past number of decades, oral history has transformed the practice of contemporary history. It is particularly useful for groups who might have otherwise been hidden from history, including women with disabilities, and in gaining personal interpretations of history and personal meanings of lived experience.(Robert Perks & Alistair Thomson, 2016, p. xiii) Louise Douglas et al. argued that oral history has uncovered forgotten or hidden voices, using the recorded interview as a vehicle for recovering the experiences and opinions of many individuals and marginalised groups.(Corinne Manning, 2010) Another and very significant role for oral history is 'anti-history', by-passing the established record with testimony from those who provide authentic eye witness accounts.(Sheena Rolph & Jan Walmsley, 2006, p. 84) Thompson notes that while "oral history is not necessarily an instrument for change" it often leads to a "shift of focus" in which the point of view of the less powerful players in a social context also get a chance to express themselves. This suggests that the use of oral histories in disability research could lead to a new view of social history, and could help create a deeper understanding of cultural conditions which affect everyone. (Karen Hirsch, 1995)

Oral History and Feminism

Feminists who work with oral history methods want to tell stories that matter.(Katrina Srigley et al., 2018, p. 1) Feminist oral historians have made significant contributions to theoretical and methodological developments in oral history, illuminating issues about oral history relationships and the interconnections between language, power and meaning.(Robert Perks & Alistair Thomson, 2016, pp. 6–7) Joan Sangster's career as a feminist oral historian points to the symbiotic connection between oral history and feminism since the late 1960s. Realising the possibilities of the oral history interview creates a shift in methodology from information gathering, where the focus is on the right questions, to interaction, where the focus is on the process, on the dynamic unfolding of the subject's viewpoint. It is the interactive nature of the interview that allows us to ask for clarification, to notice what questions the subject formulates about her own life, to go behind conventional, expected answers to the woman's personal construction of her own experience.(Robert Perks & Alistair Thomson, 2016, p. 190) In their chapter, Kim Rubenstein and Anne Isaac look at an oral history project that Rosemary Kayess was part of. They say that her distinctive contribution of human rights perspective to drafting of international disability law was born from her lived experience and activism as well as her professional experience. Making available her perspective is born from the essential feminist principles that recognises the personal is political, and the lived experiences of a woman is fundamental to understand the experience of power in society and remedy the many inequalities that continue to face our society. (Kim Rubenstein & Anne Isaac, 2019, pp. 338–358)

Oral History and Disability

The disability rights movement has so far had little effect on historical scholarship. Oral history interviews with disabled people are adding a viewpoint that has been ignored because it has been assumed that disabled people do not have an articulate view of their circumstances that differs from other views. (Fred Pelka, 2012, p. 4) Scholars in the humanities are just beginning to discover that disabled people have a unique perspective on life informed by their disability experiences. (Fred Pelka, 2012, p. 4) The growth of disability studies as an academic field and the emergence of disability history at once reflect and speak to recent improvements in the political and social status of people with disabilities. As a result, disability activists have recently begun to work to establish oral history projects or other cultural disability studies. (Fred Pelka, 2012, p. 4) More extensive oral history interviews with a variety of disabled individuals, those who are involved in the disability rights movement as well as those who chose not to be involved, could shed light on the variety of relationships disabled people have with the cultural groups with whom they live and interact. (Karen Hirsch, 1995) Fred Pelka in the book What we have done: An oral history of the disability rights movements notes that the very notion that people with disabilities are entitled to define their own identity rather than having it imposed on them by outside authorities is itself unprecedented. The historical record shows that disability has been defined by the non-disabled majority and that the treatment of people with disabilities has been inextricably linked to prevailing social attitudes about the physical and psychological difference. (Fred Pelka, 2012, p. 4) In the introduction to her book, Alice Wong talks about the importance of stories for creating change. Her Disability Visibility Project records oral histories of people with disabilities and is archived in the Library of Congress. What started out as a small project has grown into a movement and has had political influence. (Alice Wong, 2020, pp. xv–xxii) The power of conversation in the face of inequality, ableism and oppression is a powerful force. She says that through our stories, our connections and our actions, disabled people will continue to confront and transform the status quo. (Alice Wong, 2020, pp. xv–xxii) Pia Justesen uses oral history as a methodology in From the Periphery and talks about trying to understand the complex nature of disability-based discrimination and exclusion as well as the underlying causes in focusing on the individual and seeing what discrimination looks and feels like for people who experience it.(Pia Justesen, 2019, p. xvii) Kim Rubenstein and Anne Isaac when reflecting on Rosemary Kayess and her oral history they talk about lived experience recorded through oral history and made available to the public means that more people will be interested in changing the way power is exercised in society. (Kim Rubenstein & Anne Isaac, 2019, pp. 338–358) Oral history has become an important collaborative research method used by many academics when working with people with learning disabilities. The importance of oral history and narrative accounts by people with learning difficulties and people associated with them has been increasingly acknowledged in the literature since 1990. (Sheena Rolph & Jan Walmsley, 2006, p. 81) Life history which is closely related to oral history and will be drawn on for this study is a form of research and has enabled people with limited literacy skills to contribute knowledge about their experience of living with learning disabilities in different social, political and cultural contexts. Life histories and life stories are ideally suited to participatory work between people with learning disabilities and researchers because this is an area where people have something unique to say, and where the researcher, as a 'writing hand' can make a vital supporting contribution to the project, rather as a ghost writer does in constructing the autobiographies of the rich and famous. Many people with learning difficulties, learning from ideas of empowerment and the precepts of self-advocacy, are enthusiastic about the idea of recording their life stories, and researchers in the field are regularly approached by individuals who want help in recording their stories. (Sheena Rolph & Jan Walmsley, 2006, p. 84) Life histories and life stories methods are becoming increasingly established approaches to narrative, and both are accompanied by different ethical issues. Whereas much participatory research in learning disability runs the risk of co-opting people into projects they would not have chosen themselves, this is less likely to be the case with life histories.(Sheena Rolph & Jan Walmsley, 2006, p. 82) Corinne Manning explains how this kind of research has provided information previously unavailable in archives. It allows interviewees to share memories and express opinions that were lacking in traditional archival sources as well as bringing to life an institutional world through first-hand narratives.(Corinne Manning, 2010, pp. 160–161) It is hard to overstate how resistant and pervasive is the cultural assumption that people with disabilities cannot speak for themselves. Thus while there are many oral history projects that need to be done, the most important are those that deal with disability experiences as they have been lived by disabled people, and that can give voice and interpretive authority to people with disabilities themselves, not only to their advocates, their teachers, or their parents. (Karen Hirsch, 1995) Feminist scholars have discovered the need to study the interaction between gender and such other factors as class and ethnicity; likewise, disability scholars must consider the areas where gender, ethnicity, and class intersect with disability to make up the total lived experience. As a social movement, the disability rights movement has become increasingly inclusive and aware of the need to associate with all kinds of other minority groups. Disability activists need to advocate for oral history projects, to participate in local history projects, and to work with and work as disability scholars in focusing the questions, interpreting the findings and developing the language and images that can begin to give the disability community its history. (Karen Hirsch, 1995)

Conclusion

This short piece of writing has provided an overview of oral history and how it fits with the study. The beginning of the chapter looked at the study in question so that the reader could relate and understand the rationale for the choice of this methodology. Oral history fits well in both disciplines and movements and has shown to work with both academic and non-academic projects. It is particularly useful in ensuring that those who may have traditionally been hidden from history can tell their stories and be heard. The fluidity of the nature of oral history allows it to be adapted and used in the proposed project. The chapter should have provided the reader with and understanding of the significance of using oral history as a methodology within the disability movement and in examining activism of women with disabilities in both the disability and feminist movement and in amplifying the voices of women with disabilities and their experience of participation.

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13 Human rights compliance: what is the right approach?

Colin Caughey

Abstract

Academics have invested significant effort in developing theories around human rights compliance. Each theory attempts to explain what motivates a state to bring an end to human rights abuses and to take measures which guarantee human rights compliant. This article specifically considers the relevance of the theories in the context of the UN CRPD. The article considers how the findings of theorists will assist civil society organisations who are seeking to utilise the human rights standards and the human rights system to further their policy objectives. The various theories presuppose the willingness of civil society organisations to invest significant resources in contributing to the human rights system. However theorists rarely consider whether engaging in the human rights system enhances the effectiveness of civil society organisations. This article seeks to consider how the international human rights system presents civil society organisations with opportunities to effect change which would otherwise not be open to them. The various theories are grouped into three categories: rational actors, constructivists and those advocating acculturation. Rather than seeing these as competing theorists I advocate viewing them as three separate legitimate approaches to human rights compliance which a civil society organisations may develop to achieve their objectives. The selection of an effective approach is dependent upon the circumstances in the target jurisdiction and the potential response by the international system. The article acknowledges that international human rights may not always be the most effective route to an effective remedy. It invites advocates of human rights such as national human rights institutions to critically assess how they educate and engage with civil society organisations. Overall it encourages human rights advocates to ensure domestic civil society organisations are able to make informed assessments of the added value which international human rights can bring to their advocacy efforts.

Key Words: Human rights compliance, Effectiveness, Disability, Civil Society Organisations, National Human Rights Institutions

The history of human rights is one of exponential growth. Michael Ignatief has highlighted that human rights has become "*the lingua franca of global moral thought*".[1] States justify their actions and inactions by reference to the rights of individuals and civil society define their advocacy positions with reference to international standards. Despite these developments the chasm between the promises contained within international human rights instruments and the lived experience of persons with disabilities remains wide.

With nine UN human rights treaties each with its own committee of experts, the human rights industry continues to grow and civil society organisations (CSOs) continue to invest

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[1] Michael Ignatieff, Human Rights as Politics and Idolatry (Princeton University Press 2001) 53

significant resources in engaging with the system. CSOs representing marginalized groups have sought to augment their domestic advocacy activities through engaging in international advocacy campaigns for the development of bespoke international norms.[2] In 2006 the UN Convention on the Rights of Persons with Disabilities (UNCRPD) was opened for signature at the UN General Assembly. As Rasmussen & Lewis have stated *"the CRPD was the first UN Convention with significant civil society input in its drafting process. In fact, much of the final text incorporates that drafted by civil society"*.[3]

Javed Abidi, Chairperson, Disabled Peoples' International, commenting in 2014 highlighted *"even though countries are competing with each other in a race to ratification, its implementation thus far is abysmally poor"*.[4] The experience in the preceding six years have not seen a marked improvement with many states introducing extensive austerity measures with damaging impacts for persons with disabilities and state responses to the Covid crisis failing to prioritise the rights of persons with disabilities.

A significant body of literature has developed considering how international human rights compliance is realised. These draw on broader theories of compliance. In this article I will not focus on theoretical underpinnings but instead will focus on their practical implications. For the purposes of this article I have grouped the approaches into four separate categories, namely coercion, persuasion, managerial and acculturation.

An appreciation of these approaches to compliance is necessary to inform advocacy strategy development within DPOs. In this article I will consider the effectiveness of the approaches in the context of the CRPD. In my conclusion I will put forward the argument that the potential for states to be compelled or socially pressurised by other states to comply with the CRPD is limited. To have effect the CRPD advocates must instead seek to persuade state actors and to socialise key bureaucrats to bring about change.

Studies into Human Rights Compliance.

Numerous commentators have produced detailed research reports indicating that international human rights treaties have had only nominal if any positive impact at the grassroots level. Lead amongst these commentators Eric Posner has argued that, '*there is little evidence that human rights treaties, on the whole, have improved the well-being of people*'.[5] Quantitative studies indicate that endorsement of human rights norms rarely actually leads to changes in behaviour.[6] The robustness of a number of these assessments has been called into question.[7]

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[2] Jasper Krommendijk 'The domestic effectiveness of international human rights monitoring in established democracies. The case of the UN human rights treaty bodies' *The Review of International Organizations* volume 10, pages 489–512(2015) Pg 491

[3] Rasmussen M, Lewis O. Introductory Note to the United Nations Convention on the rights of persons with disabilities. International Legal Materials. 2007; 46(3):pg 441

[4] Cited in Mittler, P. (2016) The UN convention on the rights of persons with disabilities: Implementing a paradigm shift. In: Iriarte, E., McConkey, R., Gilligan, R. (eds) Disability in a global age: A human rights based approach, Basingstoke: Palgrave Macmillan.

[5] Eric A. Posner 'The Twilight of Human Rights Law (Inalienable Rights)' OUP 2014

[6] Cole. Wade M. 2012a. Human Rights as Myth and Ceremony? Reevaluating the Effectiveness of Human Rights Treaties, 1981–2007. American Journal of Sociology 117 (4):1131–71.

[7] Thomas Risse, The Persistent Power of Human Rights: From Commitment to Compliance (Cambridge University Press 2013)

The task of attributing changes in domestic laws and practices to international treaties is complex and is not always helpful as it can ignore other levers of change.[8] However even advocates of human rights such as Hafner Burton acknowledge that, *'Legal institutions for the promotion and protection of human rights are multiplying but their effects are difficult to distinguish and not always positive'.* [9]

International treaties are often characterised as being analogous to contracts in municipal law.[10] In the words of Mathew Craven international treaties are *"consensual arrangements instituting, through the medium of legal rights and duties, a reciprocal exchange of goods or benefits"*.[11] The desire to obtain a reciprocal exchange of goods or benefits can *'sustain cooperation and induce compliance'*.[12]

Human rights treaties relate to the way states treat individuals in their jurisdiction. In this context the principle of reciprocity is largely irrelevant. Explaining how states can be made to comply with human rights law therefore requires a more sophisticated approach which considers not only reciprocal interests but also the role of common values and of international systems. A number of approaches or theories have developed considering how states can be required to comply with their international human rights law obligations.

Coercion or Inducement

Coercive or inducement approaches to generating human rights compliance seek to increase the benefits of conformity and to increase the punishment for non-compliance.

This approach is associated with rational choice theory. Rational choice theory presupposes that states are *"rational, self- interested, and able to identify and pursue their interests"*.[13] Goldsmith and Posner as proponent of rational choice theory argues, *'States enter into treaties, in our view, because the benefits of the treaty out-weigh its costs'* .[14] In the words of Guzman, *'States must experience some gain as a result of their engagement with the international legal system, and that gain must be larger than what they invest'.*[15]

Posner and Goldsmith state that in the absence of pressure we are only likely to see compliance based on *'coincidence of interest'*.[16] Furthermore Posner and Goldsmith points out that *'treaties often require many of the parties to do nothing different from what they have*

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pg 91

[8] John Mayne 'Addressing Attribution Through Contribution Analysis: Using Performance Measures Sensibly' Canadian Journal of Program Evaluation 16(1):1-24 · January 2001

[9] Emilie M Hafner-Burton, A social science of human rights, *Journal of Peace Research* 2014 51: 273 pg 279

[10] H. Lauterpacht, Private Law Sources and Analogies of International Law (1927) 155–180

[11] Matthew Craven, Legal Differentiation and the Concept of the Human Rights Treaty in International Law, EJIL (2000), Vol. 11 No. 3, 489–519 pg 500

[12] Kal Raustiala, Compliance & Effectiveness in International Regulatory Cooperation, 32 Case W. Res. J. Int'l L. 387 (2000) pg 388

[13] A.T. Guzman, *How International Law Works: A Rational Choice Theory* (Oxford University Press 2010) Pg 17

[14] Jack L. Goldsmith and Eric A. Posner 'The Limits of International Law' (Oxford University Press 2006) pg 104

[15] A.T. Guzman, *How International Law Works: A Rational Choice Theory* (Oxford University Press 2010) pg 12

[16] Jack L. Goldsmith and Eric A. Posner 'The Limits of International Law' (Oxford University Press 2006) 262

done in the past'.[17] This view cannot be shared of the CRPD which is considered to represent a paradigm shift in states disability policy.

Rational choice approaches consider that for the international human rights system to become effective it must become hierarchal and call for the strengthening of international organisations to ensure they are able to coerce compliance from states.[18] Rational Choice theorists consider that to induce compliance the international human rights system must increase the costs of non-compliance by way of *"an effective or reliable coercive enforcement mechanism"*.[19] An example of a coercive method to bringing about compliance is the proposal for the development of a World Court of Human Rights.[20] This proposal was developed by a panel of international experts funded by the Swiss Government. The proposal reflects a view that *'states should establish effective specialized bodies with judicial powers in matters important for the realization of civil and economic rights'*.[21]

Philip Alston stated *'the notion that a single court would be given the authority to issue determinative interpretations on every issue of human rights on a global basis defies any understandings of systemic pluralism, diversity, or separation of powers'*. [22] In addition to the practical obstacles Charlesworth highlights *"giving priority to judicial mechanisms as a response to human rights violations overlooks the limited capacity of international courts to create local cultures of respect for human rights"*.[23]

The CRPD does not make provision for court processes. Megret has highlighted that the CRPD *"deprives judicial remedies of their otherwise central position in the enforcement theory of International human rights instruments"*.[24] This view is reflected in the OHCHR Handbook for Parliamentarians which emphasises that judicial processes may be *"inappropriate for resolving disputes emanating from the Convention"*.[25] The experience of the courts of state parties applying the CRPD rather supports this view. Waddington has cautioned against relying on domestic courts to effect compliance emphasising,*" courts*

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[17] Jack L. Goldsmith and Eric A. Posner 'The Limits of International Law' (Oxford University Press 2006) 89

[18] Abram Chayes and Antonia Handler Chayes 'The New Sovereignty: Compliance with International Regulatory Agreements' 1998 pg 272 *'Rational Choice* explicitly rejects the idea that mechanisms such as an internalized desire to comply with international law can influence state behaviour'

[19] Jack L. Goldsmith and Eric A. Posner 'The Limits of International Law' pg 120

[20] *Protecting Dignity: An Agenda for Human Rights, 2011 Report*, at http://www.udhr60.ch/docs/Panel- humanDignity_rapport2011.pdf (hereinafter *Protecting Dignity*), conclusions and recommendations, p. 40, paras. 110-111.

[21] *Protecting Dignity: An Agenda for Human Rights, 2011 Report*, at http://www.udhr60.ch/docs/Panel- humanDignity_rapport2011.pdf (hereinafter *Protecting Dignity*), conclusions and recommendations, p. 33

[22] Philip Alston Against a World Court for Human Rights Volume 28, Issue 2 Summer 2014 , pp. 197-212

[23] Hilary Charlesworth 'A regulatory perspective on the international human rights system' in *Regulatory Theory: Foundations and applications*, edited by Peter Drahos, published 2017 by ANU Press, The Australian National University, Canberra, Australia. Pp. 357-374 available at https://press-files.anu.edu.au/downloads/press/n2304/pdf/book.pdf Pg 360

[24] Frédéric Mégret, 'The Disabilities Convention: Towards a Holistic Concept of Rights' (2008) 12(2) IJHR 273.

[25] United Nations, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities,* October 2007, No 14-2007.

generally seem to have been utilising the CRPD as an instrument of domestic law, and to resolve a domestic matter, rather than seeking to reinforce or strengthen its status".[26]

Some commentators suggest that Treaty bodies should position themselves as a form of '*constitutional court'* and that advocates should consider concluding observations as *'akin to judgments'*.[27] Those advocating for this approach tend to emphasise the legal character of the Treaties. In my view the suggestion that simply by acting as a court State Parties will regard the Treaty bodies as a court and their decisions as legally binding is naïve. Furthermore it does not reflect the reality as demonstrated by the response of the UK Government to the CRPD Committee's inquiry into social security reform, that states can simply ignore and disregard findings of the Committee. [28]

Overall the potential for the CRPD Committee or any other body to apply the CRPD as a legally binding instrument is undermined due to the programmatic nature of the instrument. This was reflected in the judgement of the CJEU that the provisions of the Convention *'are subject, in their implementation or effects, to the adoption of subsequent measures which are the responsibility of the Contracting Parties'*.[29]

Within the coercive approach the principal role for civil society is to expose human rights abuses and bring these to the attention of sympathetic states and institutions who will in turn exert pressure on recalcitrant states to coerce compliance.[30] The mistreatment of persons with disabilities does not always appear to provoke the international outcry. Melish highlights that the *'forced segregation and warehousing in institutional facilities [of persons with disabilities]'* did not lead to a *'sustained international outcry by the global human rights community'*.[31]

Drinan highlights that nations *'experience "shame" when its conduct is perceived to be degrading, unworthy, humiliating, in essence, shameful'*, given the widespread nature of abuses of the rights of persons with disabilities that have in general been justified by the medical model of disabilities or the concept of best interests the potential to mobilise shame and induce shame is perhaps limited.[32] However it is positively noted that due largely to lobbying by the European Disability Forum the EU, which has ratified the CRPD, amended their policy on the granting of structural funds to prohibit their investment in building or

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[26] Lisa Waddington 'The role of the judiciary and its relationship to the convention on the rights of persons with disabilities' in Lisa Waddington, Anna Lawson (eds.) The UN Convention on the Rights of Persons with Disabilities in Practice. A Comparative Analysis of the Role of Courts *Oxford: Oxford University Press, 2018 pg* 582

[27] K Mechlem, 'Treaty Bodies and the Interpretation of Human Rights' (2009) 42 *Vanderbilt Journal of Transnational Law* 905. Pg 924

[28] Observations of the Government of the United Kingdom of Great Britain and Northern Ireland on the report of the Inquiry carried out by the Committee under article 6 of the Optional Protocol to the Convention-Advance Unedited Version CRPD/C/17/R.3 03 Nov 2016

[29] Case C-363/12 Z v A Government department, The Board of management of a community school, ECLI:EU:C:2014:159.

[30] Emilie M Hafner-Burton Sticks and Stones: Naming and Shaming the Human Rights Enforcement Problem *International Organization* 62, Fall 2008, pp+ 689–716

[31] Tara J. Melish An Eye Toward Effective Enforcement: A Technical-Comparative Approach to the CRPD Negotiations in Human rights and disability advocacy*, Sabatello & Schulze, eds., Penn. University Press, 2013 pg 72*

[32] Drinan, R.F. 2001. *The mobilization of shame.* New Haven: Yale University Press pg 32 For further discussion see Eunjung Kim (2011) 'Heaven for disabled people': nationalism and international human rights imagery, Disability & Society, 26:1, 93-106

renovating institutional care settings. Therefore inducing compliance through the lure of structural funds.

Whilst disability advocates can potentially influence the crtieria for support and aid provided by sympathetic states as Krommendijk highlights "*the extent to which states are willing to coerce other states to comply in the field of human rights is limited*".[33]

Inducements can be created at the domestic as well as the international level. In the words of Moravcsik, *'Societal ideas, interests, and institutions influence state behavior by shaping state preferences, that is, the fundamental social purposes underlying the strategic calculations of governments'*.[34] This is particularly relevant in democracies in which the electorate can punish the government.

The extent to which compliance with the CRPD will influence the electorate is questionable. Schur has highlighted in US politics, *'People with disabilities comprise an increasingly powerful voting bloc'*.[35] However persons with disabilities have struggled to harness this potential political power.[36] Ginsburg and Rapp '*The ongoing mobilization of disability publics is crucial but complex to achieve'*.[37]

Persuasion

A second approach to compliance emphasises the normative value of international norms and *'the persuasive power of legitimate legal obligations'* .[38] This approach is associated with constructivist theories which suggest that *"states are best understood as the product of, and denizens of, a socialized environment"*.[39] For constructivists, *'rules and norms ..condition actors' self-understandings, references, and ultimately their behavior'*.[40] In the words of Beth Simmons *"Persuasion depends on the power of argumentation and deliberation as distinct modes of social interaction which when successful changes what an actor values and sometimes even his or her very identity"*.[41] Civil Society organisations play a central role in persuading states to internalise social norms at both the international and domestic level.[42] To effectively persuade CSOs must develop opportunities to present their arguments.

Harold Koh emphasises that participation in the international system of human rights enhances the capacity of states to become *"discursively competent"* in human rights and to

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[33] Jasper Krommendijk 'The domestic effectiveness of international human rights monitoring in established democracies. The case of the UN human rights treaty bodies' *The Review of International Organizations* volume 10, pages489–512(2015) Pg 492

[34] Andrew Moravcsik Taking Preferences Seriously: A Liberal Theory of International Politics *International Organization* 51, 4, Autumn 1997, pp. 513–53 pg 513

[35] Rutgers School of Management and Public Relations https://smlr.rutgers.edu/news/voter-turnout-surges-among-people-disabilities

[36] Faye Ginsburg Making Disability Count: Demography, Futurity, and the Making of Disability Publics

[37] Faye Ginsburg, Rayna Rapp, Cripping the new normal: Making disability count ALTER, European Journal of Disability Research 11 (2017) 179–192 pg 190

[38] Hathaway, 'Do Human Rights Treaties Make a Difference?', 112 Yale L.J. (2002) 1935 pg 1955

[39] Kal Raustiala, Compliance & Effectiveness in International Regulatory Cooperation, 32 Case W. Res. J. Int'l L. 387 (2000) pg 405

[40] Simmons BA. International Law. In: Handbook of International Relations. (Sage Publications ; 2012). Pg 357

[41] Ibid pg 371

[42] Finnemore and Sikkink. 1998. International norm dynamics and political change. International Organization 52 (autumn): 887-917 pg 900

develop their 'internal value set'.[43] CSOs through participating in both international processes and domestic reporting arrangements can present their arguments and suggestions for reform to bring about compliance.

At a domestic level Koh emphasises processes of social, political and legal internalization of international norms.[44] Gerard Quinn has emphasized, *'process-based innovations are the key to the success of the convention'.*[45] The CRPD places a strong emphasis on the inclusion of persons with disabilities in decision making as a way of guaranteeing compliance. In recent years a range of sophisticated techniques for internalisation at the political level have been developed. These include robust monitoring activities, human rights impact assessment and mainstreaming activities. In the words of Sonia Cardenas human rights advocates seek to have these approaches *"reflected in state bureaucracies and their organisational routines and templates, which can reinforce expectations about compliance and encourage sustainable habits'* and *'consistent and comprehensive approaches'* to human rights norms.[46]

Through utilising these processes CSOs can play a key role in vernacularizing human rights standards into domestic protections or in the words of Gerard *Quinn 'translating the 'majestic generalities'* of the Convention into practice'.[47] CSOs must persuade and cooperate with state actors to translate the requirements of the CRPD into workable policy solutions that deliver the promises of the Convention in the real world. National action plans can provide a policy vehicle for translating the commitments within the CRPD into domestic initiatives.

Managerial Approaches

Managerial approaches to compliance, championed by Chayes and Chayes, highlight that non-compliance is often a result of limited statehood or ineffective management by state parties which inhibits the ability of states to *'carry out their undertakings'*.[48]

Managerial approaches to compliance are particularly relevant to the CRPD due to extensive nature of the undertakings made by state parties. Love et. al. highlight that the CRPD calls for *"fundamental realignment of the accepted and ingrained norms and procedures that have dictated how disability policy is made and who gets to participate in that process".*[49] *The CRPD* recognises that states must adapt their structures to ensure effective implementation through placing a requirement on states to establish CRPD focal points. The establishment of

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[43] J. Brunnée and S.J. Toope, 'International Law and Constructivism: Elements of an Interactional Theory of International Law', 39 Columbia J Transm. L (2000) *pg* 27

[44] Koh, Hongju (1997) "Why Do Nations Obey International Law?", The Yale Law Journal, vol 106, no. 8, pp. 2599-2659

[45] Gerard Quinn, The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability, 15 Tex. J. on C.L. & C.R. 33 (2009)

[46] Sonia Cardenas, "National Human Rights Institutions and State Compliance ," in, Human Rights, State Compliance, and Social Edited by Ryan Goodman, and Thomas Pegram, pp 29-51 pg 37

[47] Gerard Quinn, 'Disability Rights: An Important Test for Open Society' Open Society Foundation 2013

[48] Abram Chayes and Antonia Handler Chayes 'The New Sovereignty: Compliance with International Regulatory Agreements' (Harvard University Press 1998)
pg 14

[49] Laufey Love, Rannveig Traustadottie & James Rice, Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing a Seat at the Table, 8 Laws 1 (2019).

such focal points assist in the development of policy capacity facilitates *'strategic co-ordination capacity'* across Government.[50]

Chayes and Chayes highlight that the real object of many treaties is not the regulation of state behaviour but of the behaviour of private individuals.[51] This is a particular feature of the CRPD which seeks to address substantive inequality experienced by persons with disabilities across the full range of the life course. Broderick highlights *'the CRPD's expansive view of the state's role'*. The CRPD places extensive obligations on the state to protect persons with disabilities from abuses by private individuals. To realise compliance states often have to address *a 'deficit in domestic regulatory capacity'*.[52] Consider for instance the issue of discrimination against persons with disabilities in the workplace. To address the prevalence of work based discrimination requires a sophisticated approach by the state. In addition to legislation prohibiting discrimination a state must develop *'detailed administrative regulations and vigorous enforcement efforts*'.

Acculturation

A number of commentators have highlighted the socialising influence of other states in encouraging human rights compliance. Geisenger and Stein highlight that states seek to be esteemed members of the international community and highlight that the high number of states ratifying the UN Convention on the Rights of Persons with Disabilities *was 'a by-product of states wishing to be part of a global community that came to be overwhelmingly in favor of recognizing the human rights of persons with disabilities'*.[53]

Goodman and Jinks characterise the impact of the international human rights system on states as a process of acculturation. They define acculturation as, *'the general process by which actors adopt the beliefs and behavioural patterns of the surrounding culture'*.[54] Rather than emphasising the strength of norms Goodman and Jinks emphasise the strength of *'the properties of the relationship of the actor to the community'*.[55] Goodmam and Jinks focus on the role of acculturation in bringing about '*the state's conformity to global models appropriate behaviour'* such as women's suffrage.[56]

Whilst processes of acculturation have played a role in encouraging states to ratify the CRPD, its significance in encouraging the adoption of the norms contained within the CRPD is not as

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[50] Mathew Flinders, 'Governance in Whitehall' Public Administration Vol. 80 No. 1, 2002 (51–75)

[51] Abram Chayes and Antonia Handler Chayes 'The New Sovereignty: Compliance with International Regulatory Agreements' (Harvard University Press 1998)

[52] Abram Chayes and Antonia Handler Chayes 'The New Sovereignty: Compliance with International Regulatory Agreements' (Harvard University Press 1998)
pg 14

[53] Alex Geisinger & Michael A. Stein, Rational Choice, Reputation, and Human Rights Treaties, 106 MICH. L.REV. 1129 (2008).

[54] Goodman R and Jinks D (2004) 'How to Influence States: Socialization and International Human Rights Law',Duke Law Journal, Vol. 54 (3), pp. 621-703 Pg 626 , see further Ryan Goodman and Derek Jinks *'Incomplete Internalization and Compliance with Human Rights Law'*. *EJIL* (2009), Vol. 20 No. 2, 443–446

[55] Goodman R and Jinks D (2004) 'How to Influence States: Socialization and International Human Rights Law',Duke Law Journal, Vol. 54 (3), pp. 621-703 Pg 643

[56] Goodman R and Jinks D (2004) 'How to Influence States: Socialization and International Human Rights Law', Duke Law Journal, Vol. 54 (3), pp. 621-703 Pg 667

evident. This is because many of the norms contained within the CRPD depart significantly from existing practices across states and cannot be considered currently to be *'internationally legitimated norms'*.[57] For instance the CRPD Committee are yet to identify a state which has complied with the requirement to exclusively adopt supported decision making procedures to the exclusion of substitute decision making.

Goodman and Jinks theory focuses on the macro state level. However as they acknowledge socialisation takes place at a micro level. Civil society organisations can play a key role in socialising state institutions, decision makers and bureaucrats towards compliance. Peter Haas highlights the importance of epistemic communities to policy development processes, these are recognised professionals with *'authoritative claim to policy-relevant knowledge'* in a chosen area.[58] Epistemic communities can include state actors, academics and civil society actors. Human rights law, with its international application, can provide a basis for the development of an epistemic community or can be influential in their thinking.[59]

Rugge highlights that epistemic communities develop *'a dominant way of looking at a social reality'*.[60] In the context of international law, epistemic communities often form into interpretive communities who can act as advocates of distinct normative visions.[61] They can also play a key role in processes of vernacularisation. The CRPD in numerous ways nurtures the development of epistemic communities around disability rights. The requirement to develop a monitoring mechanism under Article 33(2), which must ensure the participation of civil society organisations is an innovative measure. This body provides a forum for the development of epistemic communities within state parties who can seek to influence and engage with decision makers and bureaucrats.

This reflects the view of Gerard Quinn that the CRPD provides institutional machinery for transforming the political process. Civil society organisation through the development of *'new political entrepreneurial skills'* can put forward *'blueprints for change'* which become dominant paradigm within disability policy which decision makers and bureaucrats seek to be associated with through adapting their approaches.[62]

Conclusion

In my assessment of the approaches to compliance I believe I have demonstrated that an approach based on coercion in the context of the CRPD is impracticable. Instead a CSO

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[57] Ryan *Goodman*, Derek *Jinks, Socializing States*: *Promoting Human Rights through International Law*, Oxford University Press, New York: 2013

[58] Haas, Peter M. 2000. "International Institutions and Social Learning in the Management of Global Envi- ronmental Risks." *Journal of Policy Studies* 28 (3): 558–75.

[59] J. Christopher McCrudden, ''Mainstreaming and Human Rights,'' in *Human Rights in the Community: Rights as Agents for Change*, ed. Colin Harvey (Hart, 2005).

[60] John Gerard Ruggie, 'International Responses to Technology: Concepts and Trends' International Organization, Vol. 29, No. 3, International Responses to Technology (Summer, 1975) 569

[61] *Andrea Bianchi*, *Daniel Peat*, and *Matthew Windsor* (eds). Interpretation in International Law. Oxford: Oxford University Press, 2015

[62] G. Quinn, "Resisting the 'temptation of elegance': can the Convention on the Rights of Persons with Disabilities socialize States to right behaviour?", in The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives, O.M. Arnardóttir and G. Quinn, eds. (Leiden, Martinus Nijhoff Publishers, 2009) pg 256

should seek to persuade decision makers of the value of the CRPD. In doing so advocates should consider how key decision makers can be socialised to the CRPD approach. Noting the work of Chayes and Chayes advocates need to appreciate and be sympathetic to the challenges which states face in terms of resources and policy expertise in bringing about implementation.

The CRPD more so than any previous Convention puts in place an architecture which CSOs can utilise as they seek to persuade and socialise decision makers. The obligation on Government to consult with persons with disabilities creates opportunities for CSOs to present their arguments collectively. The CRPD focal point provides a sympathetic habitat within Government which can offer CSOs assistance in framing their arguments and provide insights into Government. Thirdly the independent mechanism provides an independent structure which can provide a forum for the fostering of epistemic communities.

Utilising this framework I believe that CSOs can make a positive contribution in persuading states towards compliance by developing positive relationships with the independent mechanism and the focal point to ensure that compliance with the CRPD is seen as an essential aspect of good policy making.

14 A discussion of theories for understanding the involvement of the international disability movement in promoting the implementation of the UN Convention on the Rights of Persons with Disabilities

Hanxu Liu

Abstract

As disability movements spread around the world, it nurtures Disabled People's Organisations (DPOs) and builds the foundation to move their actions to the global arena. There has been exhaustive research on the details of DPOs' successful participation in creating the first international human rights instrument for persons with disabilities –the UN Convention on the Rights of Persons with Disabilities (CRPD). However, much less is known about the potential of DPOs' extended engagement with the UN human rights mechanisms in promoting and monitoring the national implementation of the CRPD. This article aims to address this knowledge gap by setting up a theoretical foundation to understand the importance and characteristics of global disability movement's engagement with international human rights mechanisms, and linkage to the effectiveness of the CRPD implementation. The literature review presented in this article discusses three areas of theory: critical theory and disability studies, state compliance theory, and theory of social movement and participation. Implications emerge from these theories could be beneficial for future multidisciplinary studies attempt to explain or evaluate DPOs advocacy in national, regional and international policy and law making process with a view to implement and monitor the CRPD.

Introduction

Disabled People's Organisations (DPOs) have much experience with the UN's human rights actions. Their efforts led disability rights movements to the international political arena, and eventually facilitated the creation of the UN Convention on the Rights of Persons with Disabilities (CRPD).[1] DPOs formed into regional and international alliances and were among the leading actors in the negotiation, contributing to establishing the principles in the CRPD.[2]

As the first international legally binding instrument that provides comprehensive protection of human rights of persons with disabilities, the CRPD establishes a 'paradigm shift' to a

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[1] United Nations General Assembly (UNGA), Convention on the Rights of Persons with Disabilities (CRPD) (adopted 13 December 2006, entered into force 3 May 2008) GARes.61/106.

[2] Degener T and Begg A, '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).

social and human rights model of disability.[3] Called an 'implementation convention', the CRPD puts existing human rights into practice for persons with disabilities.[4]

DPOs' (along with other civil society organisations) role in the drafting process of the CRPD has been described as a 'unique' example amongst UN human rights instruments.[5] Echoing the "nothing about us without us" mantra from the disability movement, the CRPD established a relatively robust mechanism to secure DPOs' engagement.[6] State Parties are required to 'closely consult with and actively involve with' persons with disabilities and their representative organisations in decision making processes and achieve 'full and effective participation' in the national implementation and monitoring of the CRPD.[7] Within the UN human rights mechanism, guidelines and instructions are established to allow and encourage DPOs' direct involvement with the procedures in human rights bodies, such as the CRPD Committee, the Human Rights Council and Special Procedures, to monitor the implementation of the CRPD. [8]

The UN human rights mechanisms have been questioned on its effectiveness in persuading states to comply with international human rights norms.[9] Even though the CRPD is the most

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[3] Theresia Degener, 'A New Human Rights Model of Disability' 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), 42.

[4] See United Nations Meeting Coverage and Press Release 'Committee Negotiating Convention on Rights of Disabled Persons Concludes Current Session on Persons with Disabilities' (2005) <https://www.un.org/press/en/2005/soc4680.doc.htm> accessed 25 April 2018.

[5] Theresia Degener, 'Inclusive Equality and the Human Rights Model of Disability – 10 Years Jurisprudence of the United Nations Committee on the Rights of Persons with Disabilities' (Theo van Boven Lecture, Maastricht University, 3 December 2018) <https://www.bodys-wissen.de> accessed 22 November 2019.

[6] See 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; UN Human Rights Council, 'Report of the Special Rapporteur on the Rights of Persons with Disabilities (Thematic Studyon Deprivation of Liberty of Persons with Disabilities)' (2019) UN doc A/HRC/40/54; Committee on the Rights of Persons with Disabilities, 'Rules of Procedure' (2016) UN doc CRPD/C/1/Rev.1; 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; and 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.

[7] 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 6), para 3, 21-41.

[8] UN General Assembly (n 1). Art. 34; UNGA, 'Human Rights Council' (adopted 3 April 2006), A/RES/60/251; Manca L, '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' (n 6).

[9] Eric A Posner, *The Twilight of Human Rights Law* (Oxford University Press 2014), 69-76; Oona Hathaway, 'Do Human Rights Treaties Make a Difference?' (2002) 111 Yale Law Journal 1942.

quickly ratified international human rights treaties, it will not translate into human rights compliance among the states effortlessly.[10] Degener and Quinn both noted the importance of DPOs participation in monitoring to reinforce its implementation.[11] Therefore, it is not surprising that many DPOs consider engaging in the treaty body's state monitoring process as one of their crucial tasks.[12]

This article aims to set up a theoretical foundation to understand the importance of DPOs participation in CRPD-oriented studies, the linkage between their interactions with UN human rights mechanisms in promoting states' compliance to the CRPD, and interpreting the level of their engagement in such processes.

In the following sections, this article discusses theories under three themes. These theories are drawn from various disciplines, covering legal, social and political studies. The first section reviews critical theory in relation to the understanding of disability in research and legal instruments, followed by human rights compliance theory that explains civil society as a crucial stimulus to states' compliance of international human rights norms. The last section considers theories from social movements and analyses DPO engagement types.

From Critical Theory to Human Rights Model Of Disability

Critical theory has influenced scholars in disability and legal studies who were instrumental in constructing the understanding of disability, and later influenced disability policies and laws worldwide, including the CRPD.[13] This section looks backwards into key thoughts in critical theory, disability studies, and arguments on models of disability in order to explore the theoretical meaning and purpose of DPOs participation that is embedded in the CRPD.

Developed as a social philosophy, critical theory scholars critique social reality, identifying the actors and practical goals for social transformation.[14] A key theme of critical theory is challenging the assumption and status of social norms and power structures, which leads to

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[10] Theresia Degener, 'A Human Rights Model of Disability' in Peter Blanck and Eilionoir Flynn (eds), *Routledge Handbook of Disability Law and Human Rights* (Routledge 2016), 31-32.

[11] ibid; Gerard Quinn, 'Resisting the "Temptation of Elegance": Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?' in Oddný Mjöll Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons With Disabilities: European and Scandinavian Perspectives* (BRILL 2009), 255-156.

[12] 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).

[13] Critical theory, stemming from Marxism, was developed by the Frankfurt School to analyse the structure of state and economy in the new social formation of capitalism in the twentieth century. More on discussion of critical theory, see Douglas Kellner, 'Critical Theory Today: Revisiting the Classics' (1993) 10 Theory, Culture & Society 43; Barry Hindess, 'Marxism', *A Companion to Contemporary Political Philosophy* (John Wiley & Sons, Ltd 2017), 389.

[14] James Bohman, 'Critical Theory' in Edward N Zalta (ed), *The Stanford Encyclopedia of Philosophy* (Winter 2019, Metaphysics Research Lab, Stanford University 2019) <https://plato.stanford.edu/archives/win2019/entries/critical-theory/> accessed 17 August 2020.

inequality in societies.[15] Critical theorists seek to uncover the factors that maintain the underlying power dynamics in societies and promotes social transformation through political participation.[16] A leitmotif in critical theory studies is the individual's 'emancipation', in which researchers value the significance of humans' lived experience, and often read such experience alongside historical and contextual conditions to understand a particular social situation.[17] Hence, critical theory has been utilised in a range of interdisciplinary studies of identity and cultural politics, including the political participation represented in late modern social movements (more discussion in section 4).[18]

Taking a similar stance, the social-contextual understanding of disability emphasises the social barriers and exclusion that disabled people experience every day and demand changes in the power structures to end such inequality.[19] British scholars in disability studies distil the concept of the social model of disability from the 1960s UK disabled people's movement.[20] The main idea of the British social model of disability focuses on barriers in attitudes, the environment and other structures in society in the creation of compromised life opportunities, departing from traditional bio-medical and individual views of disability.[21] Despite many criticisms against this model for conceptual and practical reasons from both disability studies and disability movements, many believe that this new understanding of disability fosters solidarity among the disability community and encourages disabled people to advocate for political and social actions to remove the barriers causing their exclusion.[22]

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[15] Ben Agger, 'Critical Theory, Poststructuralism, Postmodernism: Their Sociological Relevance' (1991) 17 Annual Review of Sociology 105. The dominant critical theorists from the Frankfurt School constitute T. Adorno, M. Horkheimer, H. Marcuse and J. Habermas, their text and main argument have been reviewed in Kellner (n 13).

[16] Kellner (n 13).

[17] Helen Meekosha and Russell Shuttleworth, 'What's so "Critical" about Critical Disability Studies?' (2009) 15 Australian Journal of Human Rights 47; Shelley Lynn Tremain, 'Foucault, Governmentality, and Critical Disability Theory: An Introduction' in Shelley Lynn Tremain (ed), *Foucault and the Government of Disability* (University of Michigan Press 2005).

[18] Dan Goodley and others, 'Provocations for Critical Disability Studies' (2019) 34 Disability & Society 972, 976-977; Agger (n 15), 125.

[19] Love L, Traustadottir R and Rice J, 'Shifting the Balance of Power: The Strategic Use of the CRPD by Disabled People's Organizations in Securing "a Seat at the Table"' (2019) 8 Laws 11, 3.

[20] British disabled people's movement proliferated through the 1980s with the expansion of groups of disabled people, including the Union of the Physically Impaired Against Segregation, and British Council of Disabled People. Finkelstein Vic, 'Representing Disability' in John Swain and others (eds), *Disabling Barriers - Enabling Environments* (SAGE Publications 1993), 13.

[21] Hasler, F, 'Developments in the Disabled People's Movement' in John Swain and others (eds), *Disabling Barriers - Enabling Environments* (SAGE Publications 1993).

[22] Anna Bruce, 'Which Entitlements and for Whom? The Convention on the Rights of Persons with Disabilities and Its Ideological Antecedents' (Lund University 2014) <http://portal.research.lu.se/portal/en/publications/which-entitlements-and-for-whom-the-convention-on-the-rights-of-persons-with-disabilities-and-its-ideological-antecedents(e74e549e-92b7-4999-8472-8f21cfdd06f6).html> accessed 7 March 2019, 57; Len Barton, 'The Disability Movement: Some Observations' in John Swain and others (eds), *Disabling Barriers - Enabling Environments* (SAGE Publications 1993); Rannveig Traustadóttir, 'Disability Studies, The Social Model And Legal Developments' in Oddný Mjöll

In the US, the social model of disability was conceptualised through a 'civil rights prism' following the forerunners in minority activism.[23] Under the American equality and non-discrimination approach, the discourse of law (as a part of the social institution dealing with inequality and oppression) is examined under critical race jurisprudence, which is a school of legal thoughts influenced by social theories including critical theory.[24] Critical race theorists contend that rights and legal reform serve as a 'rallying point' to bring in and empower minorities, which has real ramifications to the survival of a poor community.[25] One of the leading critical race theorists, Crenshaw, introduces the concept of intersectionality to examine multiple burdens imposed on women of the colour under racial and gender discrimination, which has far-reaching implications for research on social stratification, including disability studies.[26]

The disability rights movement in the US followed this non-discrimination and civil rights approach.[27] The legislation was enacted that recognises the social exclusion of disabled people is due to unequal treatment from American society and prohibits such discrimination.[28] Regardless of its crucial positive impact, the non-discrimination approach shows limitations.[29] Full social inclusion of people with disabilities requires a comprehensive approach to address both negative and positive rights to be realised; a vision later materialised in the human rights model to disability, which is embraced in the CRPD.

Social models of disability provide the knowledge basis of understanding disability in the CRPD.[30] While the CRPD continue to challenge traditional paradigms of treating people with disabilities, it emphasises that disability is caused by barriers from the interaction between

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Arnardóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities* (Brill Nijhoff 2009), 10-11.

[23] Michael Stein and Penelope Stein, 'Beyond Disability Civil Rights' (2007) 58 Hastings Law Journal 1203; Degener (n 10), 36.

[24] Mark Tushnet, 'Critical Legal Studies and Constitutional Law: An Essay in Deconstruction' (1984) 36 Stanford Law Review 623. 629

[25] Richard Delgado, 'The Ethereal Scholar: Does Critical Legal Studies Have What Minorities Want Minority Critiques of the Critical Legal Studies Movement' (1987) 22 Harvard Civil Rights-Civil Liberties Law Review 301, 305-307; Kimberlé Williams Crenshaw, 'Race, Reform, and Retrenchment: Transformation and Legitimation in Antidiscrimination Law' (1988) 101 Harvard Law Review 1331, 1382. See examples of case-law that kept the housing for coloured people.

[26] David L Hosking, 'Staying the Course: The European Disability Strategy 2010-2020 Part I: Articles' (2013) 4 European Yearbook of Disability Law 73; Shelley Lynn Tremain, *Foucault and the Government of Disability* (University of Michigan Press 2005) <https://muse.jhu.edu/book/7108> accessed 18 March 2020; Meekosha and Shuttleworth (n 17), 54; Devon W Carbado and others, 'Intersectionality: Mapping the Movements of a Theory' (2013) 10 Du Bois Review: Social Science Research on Race 303; Goodley and others (n 18), 976-977.

[27] Stein and Stein (n 23). 1206-1208

[28] ibid. The legislative victory of this movement is the enactment of the Americans with Disabilities Act, 42 U.S.C. § 12101 (2000).

[29] ibid.

[30] Traustadóttir (n 22), 15-16; Anna Lawson and Angharad E Beckett, 'The Social and Human Rights Models of Disability: Towards a Complementarity Thesis' (2020) 0 The International Journal of Human Rights 1, 4.

persons and social environment.[31] Degener presents six propositions to differentiate the human rights model from social models of disability.[32] Ferri and Broderick summarised that these distinctions of the human rights model incorporated two principles- recognising their dignity and seeking inclusive equality for persons with disabilities.[33] Beckett and Lawson suggest that the social models and human rights models of disability are complementary.[34] While the social models explain and identify where reform is needed in social structures, the human rights model offers a prescriptive tool on how policy and law can advance inclusive equality.[35] The human rights model reveals a strong participative nature and provides a detailed roadmap for political and legal reform aligning with the CRPD.[36]

In conclusion, the above discussion provides an epistemological standpoint on understanding disability, the disability movement and the CRPD. Utilising modern critical theories, disability researchers from social-contextual perspective expand the discipline's boundaries to adopt multidisciplinary perspectives, centralise the authority of people with disabilities and identify advancement needed to end oppression.[37] Meanwhile, the human rights model of disability is essential for CRPD-oriented research because it codifies the participation of people with disabilities and their organisations as a priority, and gives practical guidance on implementing the human rights entailed in the Convention.[38]

Compliance theory and the role of international human rights regimes and civil society (816)

The third section covers theoretical explanations on rationality behind states' compliance with international human rights norms and standards. By illustrating the theoretical causal mechanism regarding international human rights regimes and civil society in inducing states to change behaviour in human rights practice, this section aims to justify the potential of DPOs' international advocacy in promoting the effectiveness of the CRPD.

Compliance theory studies examine the dynamics and reinforcement between international and domestic politics to understand states' motivations in adherence to international norms, which cover a range of disciplines in political, legal and social sciences. 'Compliance' and 'effectiveness' are often used together when describing the impact of international norms on domestic practice. Specifically, compliance refers to the states' behaviour in conformity with

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[31] UN General Assembly (n 1), preamble.
[32] Degener (n 3). 43-54
[33] Delia Ferri and Andrea Broderick, 'The European Court of Human Rights and the Human Rights Model of Disability: Convergence, Fragmentation and Future Perspectives' in Gerd Oberleitner and others (eds), *European Yearbook on Human Rights 2019* (Intersentia 2019), 268-271.
[34] Lawson and Beckett (n 30).
[35] Degener (n 3), 41; Lawson and Beckett (n 30), 17-18.
[36] Degener (n 3); Lawson and Beckett (n 30), 17.
[37] Meekosha and Shuttleworth (n 17), 50-51; Goodley and others (n 18), 976-977; Kellner (n 13), 43; Colin Barnes, 'Disability and the Myth of the Independent Researcher' (1996) 11 Disability & Society 107; E Stone and M Priestley, 'Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers' (1996) 47 The British Journal of Sociology 699.
[38] Lawson and Beckett (n 30). 12 &17.

international norms, whereas effectiveness implies the causal linkage between such behaviour and its cause.[39] This article emphasises theories which could be operated to justify the interactions between civil society (including DPOs) and the UN human rights machinery and lead to state actions in implementing human rights norms accordingly.

Theorists employ two logic frameworks to reveal states' motivations to abide to international norms, namely the instrumental rationality (the logic of consequences) and normative rationality (the logic of appropriateness).[40] Instrumental rationality theorists believe that states choose (or not) to comply with international norms after calculating the costs and gains from consequences.[41] Contrarily, normative rationality theorists argue the legitimacy of international legal regimes mainly persuade the states to obey the rules because it is the appropriate thing to do.[42] In addition, they state that the international human rights body relies mostly on internal incentives within a country, to generate the transnational and domestic mobilisation that induces states' to internalise human rights norms into national policies and laws.[43] In this process, international human rights regimes and the domestic actors, mainly civil society, are mutually reinforced.[44]

On that basis, recent studies on states' human rights compliance tend to combine the two logics of compliance in analysing the role of transnational effect of international regimes on states' practice. A prominent theory on transnational and domestic mobilisation causal mechanisms in international human rights compliance is the spiral model of human rights raised by Risse, Rope and Sikkink.[45] They argue that the establishment and sustainable advocacy networks among domestic and transnational actors that link up with international

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[39] Jasper Krommendijk, 'The Domestic Effectiveness of International Human Rights Monitoring in Established Democracies. The Case of the UN Human Rights Treaty Bodies' (2015) 10 The Review of International Organizations 489, 492; Hathaway (n 9), 1965.

[40] Jasper Krommendijk, 'The Domestic Impact and Effectiveness of the Process of State Reporting under UN Human Rights Treaties in the Netherlands, New Zealand and Finland: Paper-Pushing or Policy Prompting?' (2014) <https://cris.maastrichtuniversity.nl/en/publications/the-domestic-impact-and-effectiveness-of-the-process-of-state-rep> accessed 21 April 2020, 33-44; Hathaway (n 9), 1944-1960; Tanja A Börzel and Thomas Risse, 'From Europeanisation to Diffusion: Introduction' (2012) 35 West European Politics 1.

[41] Börzel and Risse (n 40); Frank Schimmelfennig, 'Strategic Calculation and International Socialization: Membership Incentives, Party Constellations, and Sustained Compliance in Central and Eastern Europe' in Jeffrey T. Checkel (ed), *International Institutions and Socialization in Europe* (Cambridge University Press 2007). B&R5;Shimmelfenning, 33.

[42] For a comprehensive review on the compliance theory, see Krommendijk (n 40), 33-44; Hathaway (n 9), 1944-1960.

[43] Xinyuan Dai, 'The "Compliance Gap" and the Efficacy of International Human Rights Institutions' in Kathryn Sikkink, Thomas Risse and Steve C Ropp (eds), *The persistent power of human rights: from commitment to compliance* (Cambridge University Press 2013), 97-102; Beth A Simmons, *Mobilizing for Human Rights : International Law in Domestic Politics* (Cambridge University Press 2009), 127-133.

[44] Krommendijk (n 39). 492

[45] Thomas Risse and Steven C Ropp, 'Introduction and overview' in Kathryn Sikkink, Thomas Risse and Steve C Ropp (eds), *The persistent power of human rights: from commitment to compliance* (Cambridge University Press 2013),5; Krommendijk (n 39),495; Kathryn Sikkink, Thomas Risse and Steve C Ropp (eds), *The persistent power of human rights: from commitment to compliance* (Cambridge University Press 2013).

regimes are the most crucial in the process of states' compliance.[46] These interactions include simultaneous activities among international and transnational connections, constituting of international NGOs, international human rights institutions, and domestic actors and the state governments.[47] Together, these advocacy networks create a 'boomerang pattern' that pressure states to comply with human rights norms from 'above' (transnational mobilisation) and from 'below'(domestic mobilisation).[48] Initially, the transnational networks are the dominant actors in promoting the transition of a state's human rights compliance.[49] Theoretically, states utilise a mixture rationalities in different phases of human rights compliance, which can start with instrumental rationality, then transit to normative rationality.[50]

It is noteworthy that the legitimacy of international human rights regimes could be a crucial factor in determining the level of national compliance. The legitimacy refers to the determinacy, validation and coherence of norms, which is reinforced with the secondary rules system, the international institutions and processes adhering to the norms, such as UN treaty bodies.[51] Since these institutions often facilitate a cooperative and participatory treaty monitoring among countries, legitimacy could influence states' willingness and capacity to follow and comply with international regimes.[52] However, the perception of legitimacy is subjective among state participants, as state policymakers could have various opinions on the legitimacy of international human rights regimes, depending on a country's system, interests, and human rights types.[53] Even evidence shows the influence of the legitimacy is complementary, it could be the main reason for states' decision of not complying with human rights norms.[54] Scholars also have mixed views on whether the compliance and effectiveness of international human rights regimes require preconditions on a country's social and political setting, such as liberal domestic government with an independent and mature judiciary and robust civil society.[55]

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[46] Sikkink, Risse and Ropp (n 45).5

[47] ibid. 17-18

[48] ibid. 18

[49] ibid. 33

[50] Risse and Ropp (n 45). 12

[51] Thomas M Franck, 'Legitimacy in the International System' (1988) 82 The American Journal of International Law 705. 706

[52] Hathaway (n 9),1957; Ryan Goodman and Derek Jinks, 'Measuring the Effects of Human Rights Treaties' (2003) 14 European Journal of International Law 171,636-637; Abram Chayes and Antonia Handler Chayes (eds), *The New Sovereignty: Compliance with International Regulatory Agreements* (Harvard University Press 2009),193.

[53] Franck (n 51),706; Ian Hurd, 'Legitimacy and Authority in International Politics' (1999) 53 International Organization 379,381.

[54] Krommendijk (n 39).

[55] Franck (n 51),752; Hathaway (n 9), 1953-1954; Andrew Moravcsik, 'Explaining International Human Rights Regimes: Liberal Theory and Western Europe' (1995) 1 European Journal of International Relations 157, 178-180; Simmons (n 43), 132; Posner (n 9), 69-76.

Notwithstanding, the UN highlights the practice of human rights as stimulated by reform processes for the state to internalise such norms.[56] To conclude from the above theoretical discussion, DPOs could play a vital role in socialising states to implement the CRPD, by utilising international human rights institutions and polity as political leverage to empower their advocacy.[57] These theories could offer foundations for researchers to design research and test the causal linkage between DPOs international advocacy and a state's compliance of human rights, identifying key factors in the success or failure of the process.

Theory of Social Movements and Participation

The last section introduces social movement theories to reflect on participants, mechanisms and results expected from DPOs international advocacy or international disability movement, including their participation in the international regimes related to CRPD implementation and monitoring.

The previous section discussed the essential roles of civil society, such as DPOs, in promoting the effectiveness of international human rights regimes in domestic practice.[58] More importantly, DPOs are the primary components in worldwide disability movements, presenting the theme of self-advocacy of people with disabilities.[59]

The modern theorisation of civil society draws from critical social theorists like Gramsci and Habermas, evolving to address strong political interests in the heterogeneous public sphere in societies.[60] Theorists believe civil society provides the terrain of social movements, which are key agents in bringing the positive potential of modern civil society in societal and political transformation. [61]

Theorists who try to define contemporary social movements bring in the strengths from both European Marxist thoughts on new social movements and American scholars empirical

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[56] UN. Secretariat, 'Concept Paper on the High Commissioner's Proposal for a Unified Standing Treaty Body-Report by the Secretariat' (2006) UN Doc HRI/MC/2006/2. para 8-9.

[57] Dai (n 43),97-102; Börzel and Risse (n 40),7-8.

[58] 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 6). para.14.

[59] The slogan was first used at an international disability rights conference in the early 1990s. See Magdolna Birtha, 'Making the New Space Created in the UN CRPD Real: Ensuring the Voice and Meaningful Participation of the Disability Movement in Policy-Making and National Monitoring' (Thesis, 2014) <https://aran.library.nuigalway.ie/handle/10379/5349> accessed 5 May 2019, 41; Len Barton (n 22).

[60] For Gramsci's theory on civil society see Joseph A Buttigieg, 'Gramsci on Civil Society' (1995) 22 boundary 2 1. For discussion on Habermas' civil society theory, see Dieter Rucht, 'Civil Society Theory: Habermas' in Helmut K Anheier and Stefan Toepler (eds), *International Encyclopedia of Civil Society* (Springer US 2010) 412; Jürgen Habermas, *The Theory of Communicative Action, Volume 2: Lifeworld and System: A Critique of Functionalist Reason* (Thomas McCarthy tr, Beacon Press 1985). Also see Nancy Fraser, 'Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy' [1990] Social Text 56.

[61] Jean L Cohen and Andrew Arato, *Civil Society and Political Theory* (MIT Press 1994),ix; Bent Flyvbjerg, 'Habermas and Foucault: Thinkers for Civil Society?' (1998) 49 The British Journal of Sociology 210,214; Nick Crossley, *Making Sense Of Social Movements* (McGraw-Hill Education (UK) 2002),8.

experience of national collective actions.[62] Among them, Della Porta and Diani offers a fluid definition, which defines a social movement as a process that contains a range of activities.[63] Social movements first engage a series of conflicting actions aiming for 'political and/or cultural' social change.[64] These actions are linked with spontaneous formation of social movements, such as various autonomous organisations, as long as they engage in the sustained exchange of resources for the common good.[65] Most importantly, Della Porta and Diani argue that social movements cannot be done within one process or initiative. Collective identity is developed alongside ongoing events, which bring a common purpose of maintaining this collective mobilisation.[66] In terms of disability movements, this definition also explains the heterogeneous nature within the movement due to diversity in local disability communities.[67] Social movement organisations, like DPOs, are often the centre of social movement research, as they provide examples for understanding the characteristics and development of a movement. Theorists then explain patterns of a social movement engagement and corresponding influences on reaching its goal.

Beckett connects social movements to its core focus of 'citizenship'.[68] The different model of engagement in citizenship could be explained by the conceptual framework of 'proactive and defensive engagement' in Ellison's theory on social citizenship.[69] Ellison points out that, in late modern societies, the nature of citizenship encourages citizens' engagement '…in the pursuit, or defence, of particular interests and/or social rights'.[70] In the former proactive engagement, citizens can take political actions to 'further their own interests (or those of others) through significant interventions in forms of new demands' could lead to reshaping political and public agendas.[71] Contrarily, in the latter defensive engagement, citizens take passive forms of defensive actions against risks, such as 'the erosion of their social rights', due to the demands generated from the above-mentioned external changes.[72] Citizenship is thus viewed as a process of engagement.[73]

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[62] Nick Crossley (n 61),10-11,161; Alain Touraine, 'An Introduction to the Study of Social Movements' (1985) 52 Social Research 749, 781-782; Mario Diani and Donatella della Porta, *Social Movements: An Introduction* (John Wiley & Sons, Incorporated 2006),9.
[63] Diani and della Porta (n 62). 20.
[64] ibid, 21.
[65] ibid.
[66] ibid.
[67] Angharad E. Beckett, 'Understanding Social Movements: Theorising the Disability Movement in Conditions of Late Modernity' (2006) 54 The Sociological Review 734, 737.
[68] ibid, 748.
[69] ibid; Nick Ellison, 'Proactive and Defensive Engagement: Social Citizenship in a Changing Public Sphere': [2017] Sociological Research Online <https://journals.sagepub.com/doi/10.5153/sro.513> accessed 14 May 2020.
[70] Ellison (n 69).para 1.1
[71] ibid. para 1.2
[72] ibid. para 1.3.
[73] Angharad E. Beckett (n 67). 750

Beckett recognises the relevance of his theory on defensive engagement in understanding disability movements.[74] Whilst admitting that the defensive engagement method is necessary when people with disabilities and the groups are weak at influencing decision-making processes, Beckett suggests that it is preferable for movements to develop proactive engagement for long term benefit.[75] Proactive engagement brings out transformation in society rather than working within the existing social divisions and relations that underpinned the social exclusion in the first place.[76]

Against the above discussion, researchers also consider whether forms of participation, could guarantee DPOs' engagement in international decision making processes, as granted in the CRPD. Birtha suggests that the typology of participation developed by Arnstein, explaining the levels and power distributions of collective actions of citizen participation in policymaking, could be applied to the context of DPOs engagement.[77] Arnstein's theory is distilled from empirical studies on citizen participation of minority groups within the US governance activities.[78] Arnstein brings up a typology of eight levels of participation (see figure 1).[79] These different levels of participation correspond to the extent of citizen's power in determining political decisions, from 'non-participation' to 'degrees of citizen power'.[80] Minority citizens and their groups begin to obtain citizen power in policy planning and making process only in the top runs of the ladder by building partnership with the authority and even leading the policy plan.[81] The ladder typology of citizen participation can be generalised to analyse any social actions where people are struggling to obtain power and to receive responses from the institutions.[82]

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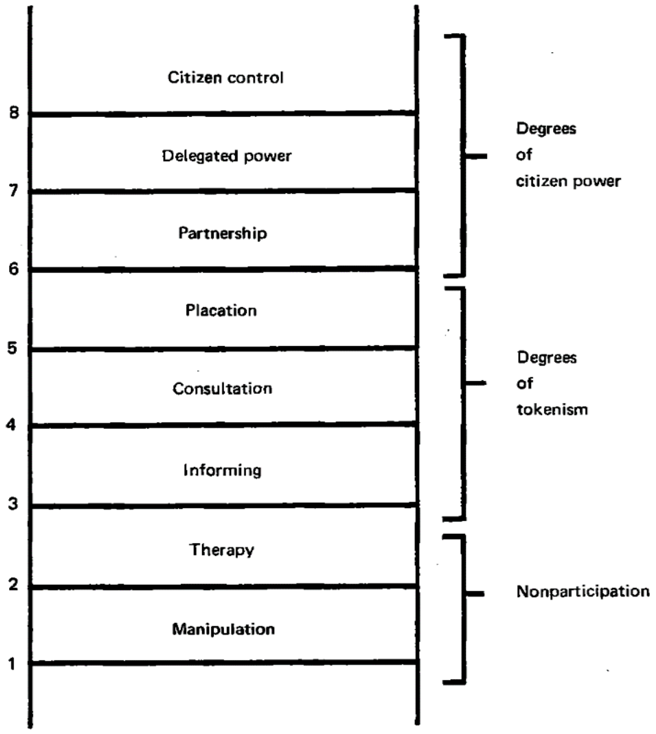
[74] ibid, 749.
[75] ibid.
[76] ibid.
[77] Birtha (n 59), 19; Sherry R Arnstein, 'A Ladder Of Citizen Participation' (1969) 35 Journal of the American Institute of Planners 216.
[78] Arnstein (n 77), 216.
[79] ibid, 217.
[80] ibid.
[81] ibid, 221-223.
[82] ibid, 217.

Figure 1: Eight Rungs on a Ladder of Citizen Participation[83]



In summary, this section provides several theories in social movements for researchers who wish to understand DPOs international advocacy in relation to the CRPD as a part of the international disability movements. Utilising the theories on participation, researchers could build a framework to assess the mechanisms of DPOs' interactions with political institutions and the genuine participation and power distribution they have achieved.

Conclusion

This article depicts three categories of theories and their application: critical theory, human rights compliance theories, and social movement theories. Critical theory and human rights model of disability first set the purpose and guide of CRPD-related studies. At the same time, analysis of two other categories of theories shows the potential analytical framework could answer questions of how and what factors make international disability movement successful in response to DPOs rise in international advocacy in promoting the implementation of the CRPD. Researchers could choose the relevant theories in guiding the research design, data collection and analysis. These theories will be useful to conduct explanatory and empirical research to reach conclusions and recommendations for future advocacy strategies in disability movements and policy developments for states to fulfil their obligations under international human rights norms. In return, such research could contribute to relevant theory development.

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[83] ibid, 217.

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