

Disability inclusion and structural change: Understanding the relationship between stakeholders in the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) programme

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## 1. Abstract

Global policies, frameworks and programmes have emerged to address the exclusion of persons with disabilities and their fundamental rights. Existing evidence aligns on the need to comprehensively understand and address disability rights initiatives in theory and practice, and this PhD contributes to the body of knowledge through examination of the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). It seeks to fill critical gaps in knowledge surrounding the mechanisms and processes of structural change in disability inclusive development.

The existing literature highlights a dearth of comprehensive research on disability rights within international development programmes. This gap is particularly evident in the limited exploration of the practical application of Theory of Change (ToC) frameworks and the dynamics of social dominance in disability inclusive development initiatives. Moreover, there is a lack of in-depth studies examining such rights-based projects in context as countries seek to implement the Convention on the Rights of Persons with Disabilities (CRPD).

The primary research question driving this thesis is: "Is the UNPRPD programme triggering structural change, and if so, how?" This overarching question guides the study's aims, which include examining the UNPRPD programme in the context of global UN frameworks, understanding the influence of capital and dominance, and investigating the processes behind the UNPRPD programme from the perspective of multiple stakeholders.

The research employs a multi-faceted methodology that combines qualitative and quantitative approaches. Theoretical and desk analyses grounded the UNPRPD programme against the existing literature and assisted in framing the country studies that followed. Case

studies in Uruguay and Serbia provide insights into the practical application of ToC, capital and social dominance theories, while statistical and Geographic Information Systems (GIS) analyses of census data offer a perspective on disability inclusion challenges. This methodological diversity enhances the depth and breadth of the research.

The research findings reveal several key insights. Stakeholder engagement dynamics significantly impacted project outcomes, with Uruguay revealing challenges in involving individuals with disabilities and Serbia highlighting the value of pre-established relationships between United Nations Country Team (UNCT) representatives and civil society. Second, the research underscores the need for adaptive and iterative Theory of Change (ToC) frameworks, developed collaboratively based on diverse partner experiences, to address potential gaps in stakeholder perspectives and enhance disability inclusion initiatives. Lastly, social dominance and capital theories prove instrumental in understanding the multifaceted nature of structural change within disability inclusive development, considering both historical and contemporary forces. Overall, these findings hold meaningful implications for policymakers, practitioners, and advocacy groups, providing valuable insights for effectively navigating the intricacies of disability inclusion.

In conclusion, this thesis contributes to a more nuanced understanding of disability inclusion in international development by addressing existing gaps in the literature. It emphasizes the need for dynamic and iterative ToC frameworks in programmatic evaluations and the importance of considering capital and social dominance theories in disability inclusive development.

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### 3. Introduction

People with disabilities are a large and diverse population, found in every country and demographic. While disability has always been a characteristic of social diversity, the recognition and inclusion of people with disabilities continues to be a challenge for global development. Societies were constructed before mainstreamed disability rights, and are built on inaccessible policies, practices and physical spaces (WHO, 2016). The long history of stigma, fear and institutionalization of people with disabilities removed them from having a voice in society, and created barriers that perpetuate exclusion (WHO, 2016).

Addressing the exclusion of people with disabilities is a complicated undertaking. Limited research exists to understand disability, as a population as well as individual disability types and the forces that compound them (Coogan, et al., 2012; Groce, 2018; Kuper & Heydt, 2019; Kuper, 2020). Several major questions arise, including: What exactly is disability? If people with disabilities are not visible in society, where are they? If we do not know who has a disability or where they are, but we know they are excluded, how can we begin to strategize a solution? These questions begin to unpack the extent to which exclusion is unknown, however it is important to recognize these barriers affect at least an estimated 1 billion people globally, and those numbers are projected to grow (WHO, 2016; WHO & World Bank, 2011). A disproportionate amount of disability occurs in the most vulnerable populations (e.g., low-income countries, children, women and older populations), evidencing multiple forms of discrimination toward groups targeted in development projects when intersected with disability (WHO & World Bank, 2011; Kuper & Heydt, 2019). As people with disabilities are systematically excluded from participating in societies and are often the hardest to reach in development efforts, disability inclusion has become a new priority for global, regional, national

and local agendas (Kuper & Heydt, 2019; World Health Organisation & UNICEF, 2022; World Health Organisation & World Bank, 2011).

Disability development at such a large scale as full global inclusion is extraordinarily difficult to capture with traditional programming, leaving much of the development process and outcomes unknown. Exclusion and inclusion express differently in diverse cultures and contexts, limiting any universal or fixed targets designed to monitor the effects of programming. To outline specific rights universally entitled to individuals with disabilities, and therefore a framework to align interventions, the United Nations have developed a Convention on the Rights of Persons with Disabilities (CRPD) outlining 50 principles mandated to ensure the fundamental rights of persons with disabilities are reflected in policy and practice across member states (UN CRPD, 2006). The CRPD institutionalizes a standard set of human rights across country contexts that hold true despite the incredible variation in societies and internal structures.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes disability as a cross-cutting issue and enshrines the rights of persons with disabilities as equal citizens in all aspects of life. The CRPD, which was adopted in 2006, represents a paradigm shift in the way disability is viewed, from a medical model to a human rights model (see *Disability Models*)(United Nations, 2006). It requires states to take proactive measures to ensure the full and effective participation of persons with disabilities in all aspects of society, including in development processes (United Nations, 2006). Despite the convention's widespread adoption and ratification by numerous countries worldwide, people with disabilities still face challenges in accessing and enjoying basic human rights (WHO & World Bank, 2011; UNDESA, 2016). The UN Partnership on the Rights of Persons with Disabilities (UNPRPD) was formed in response to these challenges, with the goal of promoting disability inclusion and social

equity (United Nations, n.d.; UNPRPD Technical Secretariat, 2016). Despite the programme's efforts, there is a lack of research on the extent to which the UNPRPD has facilitated structural change and disability inclusion. Therefore, this research aims to investigate if the UNPRPD programme has triggered structural change toward disability inclusion, and if so, how.

This chapter introduces a body of research conducted as a PhD by publication, exploring a global UN programme designed to support countries as they set out to implement the CRPD through country projects. The first section provides a closer look at the misalignment between disability at the local level and codified rights at the international level, followed by an introduction to the UN programme at the centre of this study. The next section provides an overview of the purpose of the study, research question and objectives, and methodology. The chapter concludes with a short background of existing literature and theory to provide context for the publications that follow.

### 3.1 Knowledge gap

The CRPD serves as a development tool to mobilize a rights-based model of disability by obligating attitudinal and environmental changes, and accountability to the implementation of fundamental rights made through the commitment of Member States (UNDG, 2011).

Importantly, guidelines stated in the CRPD articles represent more than linear change, as “...it challenges customs and behaviour based on stereotypes, prejudices, harmful practices and stigma relating to persons with disabilities.” (OHCHR, 2014, p. 4). The Convention, therefore, not only obligates change to the environment, but also the individuals, ideologies and relationships within and between social structures. Based on what we understand of disability exclusion, the social values, behaviors, norms and beliefs are embodied and expressed through structures (e.g., education, government, medicine) found across local, regional and global contexts seen today,

and remain relatively fixed and stable over time. Changes in these underlying principles that perpetuate exclusionary social forces are very difficult to capture in evaluations of social development projects. Implementing activities that propose to alter long held practices in established sectors requires something different than traditional aid or development.

The need for disability inclusion and implementation of the CRPD globally is widely accepted and increasingly seen in development programming frameworks (UNDESA, 2013; UNDESA, 2016; UN Enable, 2004; United Nations General Assembly, 2014; Groce, 2018; UNDP, 2018; Marshall, 2012). The United Nations (2018) emphasized the importance of disability inclusion in the SDGs and identified key areas where inclusive development efforts could be focused. Similarly, UNICEF (2019) launched a campaign for an inclusive world that highlights the importance of inclusion for all, including persons with disabilities. The UN Disability Inclusion Strategy (United Nations, 2019) provides a framework for promoting disability inclusion across all UN entities, highlighting the importance of inclusive policies and practices. Despite the increase in programming or strategy, results are difficult to monitor. Existing literature calls for diverse, quantitative and qualitative impact evaluations to better understand the effectiveness of disability-inclusive development and present methodological challenges to generating such findings, as well as to increase disability inclusion in research itself (Byrne & Kelly, 2015; Burke & Byrne, 2021; Kuper et al., 2020). Kuper et al (2020) recommend the use of a Theory of Change (ToC) to frame baseline and post-programme evaluations, but also recognise the ambiguity that persists in undefined targets, such as ‘stigma reduction’ and ‘participation’ (p. 6). Participation in particular is mandated in the CRPD, yet the process and meaning in varying disability-inclusive development contexts remains difficult to evidence, track and measure for impact.

Similarly, Schuelka asserts of disability-inclusive education, “Measuring the success of inclusive education should go beyond merely counting students to evaluate access, but should include measures of educational quality, outcomes, and experiences. (2018, p. 2)” Most literature on metrics in disability-inclusive development focus on measuring the prevalence of disability in a national population (Wissenbach, 2013; UNDP, 2018; Cobley, 2018), or country case studies finding a greater need for accessibility as a means of participation, organizational awareness or a general lack of disability intersectional programming. These findings are further supported by a systematic review of CRPD Committee Concluding Observation reports on inclusive education across 72 countries, finding widespread gaps in the realisation of Article 24 CRPD (Byrne, 2022). In the field of research itself, Priestley et al (2010) recommend participation at the ideation and inception stages of a research proposal, having seen most participation of persons with disabilities in the role of study participants. Asserting persons with disabilities and their representative organisations should play a role in setting the agenda for research inquiries further defines participation as including leadership and decision-making authority. Active participation of persons with disabilities are consistently cited as essential to disability-inclusive development and knowledge production (Burke & Byrne, 2021; Lorenzo & Joubert, 2011; Lorenzo & Coleridge, 2019; United Nations, 2006), including in the UNPRPD programmatic strategy (UNPRPD Technical Secretariat, 2016). While there appears to be consensus over key directives such as meaningful participation and non-traditional evaluation and research, there is very little evidence exploring or guiding development processes towards structural change, compounded by the global diversity of disability-inclusive development.

Limited literature on programmatic results in disability-inclusive development has been published, particularly around the development of stakeholder partnerships as enshrined in the

CRPD. Coe (2012) reported key learnings from five World Vision projects in the disability domain, including hiring persons with disabilities as part of the development team, increasing positive perception and attitudes of persons with disabilities, consistent awareness raising and strong support at the highest level of stakeholder engagement to expedite progress. A systematic review by Yesilkaya, et al. (2021) identified persistent barriers to support for children with visual impairments, despite the development of facilitating interventions. While literature was limited and Yesilkaya, et al. (2021) call for future research, exclusion remains evident, even in areas where targeted disability programming has taken place. Another example of the Portuguese Disability Movement shed light on the local and historical disability movements as it shaped structural change, however, the authors noted the continued challenges of implementing policy level changes and reducing poverty (Fontes, 2014).

In another study exploring a programmatic ToC to initiate structural change in diverse communities, Asada et al (2019) found early engagement activities such as alliance strengthening, capacity building and overall readiness for change as critical factors, prompting revisions to their initial ToC framework, especially given short programmatic timelines. Findings highlighted the programmatic need to address readiness for change as an evolving state throughout the project lifecycle and create a distinction between organizational capacity and individual leadership or technical expertise. They state,

The original ToC assumed that intervention support activities- such as still trainings- would improve individual and organizational capacity... however, this part of the ToC did not account for contextual and other factors that can facilitate or impede these processes, nor did it consider the relationship between individual and organisational capacity. (p. 384)



The study identified different forms of capacity, including staff to operationalise and coordinate implementation activities, technical experts and leadership, both high-level decision-makers and individuals “having extensive local knowledge of the community as well as influential partnerships with change agents” (p. 384). This study identifies gaps between a ToC and categories of resources needed for implementation in practice. ToCs are high-level frameworks designed to be open enough for contextual interpretation and alignment with local needs, however, studies such as these offer a meso-level analysis to define broad terms such as participation or capacity that have been problematised in the disability-inclusive development cited above. Similar evidence remains a gap in knowledge for the UNPRPD programme.

Structures refer to the framework of a society, such as policies and laws, institutions, systems and processes that inform a sense of ‘normal’ or status quo. These are often durable and widely accepted. Structural change is necessary to ensure that people with disabilities have equal access to opportunities, resources, and services as enshrined in the CRPD (United Nations, 2019), and are in line with legal frameworks and development priorities. As such, the research question for this PhD asks, *Is the UNPRPD is triggering structural change, and if so, how?* The next section will explore the existing research and identify a gap in the scientific knowledge of the UNPRPD programme, evidence on the implementation on their ToC and processes underlying structural changes.

### 3.1.1 United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD)

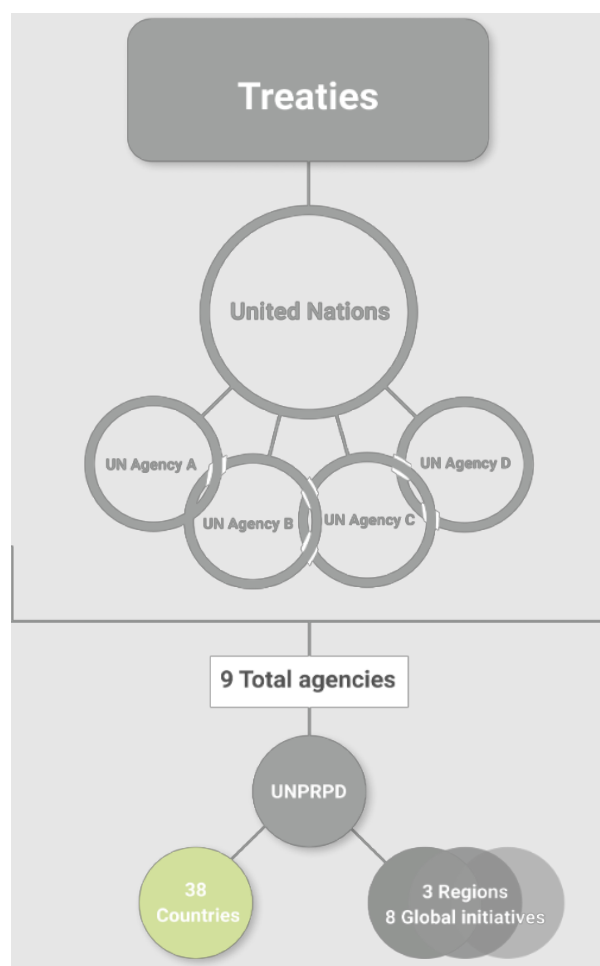
Implementing the CRPD requires collaboration and contribution of multiple UN stakeholders, as disability crosscuts nearly all structures in societies. Take for example, access to employment. Before entering the workforce, people generally participate in some form of education. The UN agency UNESCO aims to develop all aspects of education. As a precursor to

employment, barriers in education create a systematic gap in future candidates with disabilities compared to their non-disabled counterparts. The International Labour Organization (ILO) addresses labour rights in developing contexts, however, due to barriers facing people with disabilities across a lifetime, there are shortages in both supply and demand for individuals with disabilities in hiring practice (despite their capacity to work), (MacLachlan et al., 2019).

Employers could be educated about workplace accommodations and hiring individuals with disabilities, though this potential workforce has been removed from training, education, and face ableist stereotypes disqualifying them from the normative worker profile (Levitt, 2017; Marks, 1997; Marrone & Mitchell, 2020). The barriers facing people with disabilities continue across health, gender, civic participation and all other rights listed in the Convention (United Nations, 2018; UNDESA, 2016; UNDP, 2018).

The UNPRPD recognized the limitations of each thematic agency's scope in the pursuit of the CRPD and created a collaborative network to create more comprehensive programming. The result was a joint program to support countries navigating the complexity of disability development, comprised of various UN agencies (currently nine participating agencies, including: ILO, OHCHR, UNDESA, UNDP, UNESCO, UNFPA, UNICEF, UN Women, and WHO) into the Partnership on the Rights of Persons with Disabilities (UNPRPD)(UNDP, 2016) where the primary directive is to help participating Member States progressively implement the CRPD through UN Country Team (UNCT) led projects.

**Figure 1:** Diagram of the UNPRPD within the UN system



The term ‘partnership’ in the UNPRPD programme title refers to a tripartite approach, engaging UN agencies, local government and civil society (UNDP, 2016). Representatives from each entity align to support and drive the priorities set out for projects on a two-year cycle. Each entity brings their expertise to the project and aligns with the general obligation in Article 4.3 CRPD to include persons with disabilities and their representative organisations in decisions, particularly those affecting them (CRPD, 2006). This is the first UN programme to formalise engagement inclusive of disability organisations to support implementation of the CRPD.

**Table 1:** UNPRPD project countries and regional initiatives by funding round

UNPRPD Funding round	Countries or regions
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Round 1	Mozambique, Togo, South Africa, Palestine, Tunisia, Indonesia, Pacific Islands, Viet Nam, Moldova, Ukraine, Costa Rica
Round 2	Ethiopia, Uganda, Egypt, Sudan, China, India, Armenia, Tajikistan, Bolivia, Mexico
Round 3	Morocco, Benin, Zambia, Zimbabwe, Djibouti, Malawi, Namibia, Pakistan, Nepal, Cambodia, Bhutan, Timor Leste, North Macedonia, Serbia, Guatemala, Peru, Uruguay
Global and regional work streams	Support to the African Disability Forum, Pacific Enable, One UN Approach to Disability Statistics

### 3.1.2 UNPRPD reporting

The UNPRPD publishes annual progress and financial reports dating back to 2015. Up to the point of data collection in 2019, outcomes were reported in high-level results, such as the number of outcome-level transformations or percent of budget spent (MPTF, 2015; MPTF, 2016; MPTF, 2017; MPTF, 2018; MPTF, 2019). The UNPRPD defined outcome as, “The intended or achieved short-term and medium-term effects of an intervention’s outputs, usually requiring the collective effort of partners. Outcomes represent changes in development conditions which occur between the completion of outputs and the achievement of impact” (UNDP, 2016, p. 12). The reference to *short-term and medium-term effects* aligns with the two-year project lifecycle and framed the annual reporting via metrics and outputs, however, the connection between those effects and structural change was drawn primarily through their programmatic ToC and has not been reported against as of the inception of this research (UNPRPD Technical Secretariat, 2016; MPTF, 2015-2019). A holistic view of projects over multiple calendar years can be found in

another set of reports, called Connections (UNDP, 2016) and Intersections (UNPRPD Technical Secretariat, 2018), though they use the same data found in the annual reports. Both reports are produced by the UN and provide high-level summaries of the UNPRPD programme and resulting impacts by funding round.

The first two reports in 2015 and 2016 provided further quantitative progress, such as the number of outcome-level transformations reported by funding year (Table 2). For example, 30% of Round 2 (R2) projects targeted the outcome, Capable and Inclusive Institutions. 34% of reported milestones contributed to the outcome in 2015, and 40% in 2016. The report concludes the metrics show alignment between project activities and the outcomes they are striving for (2015, p. 7).

**Table 2:** Number of R2 outcome-level transformations reported by funding round and year

Outcome priority	Baseline: % of projects targeting each outcome	2015 Reported results by outcome (%)	2016 Reported results by outcome (%)
Access to services	37%	34%	26%
Capable and inclusive institutions	30%	28%	40%
Enabling legislation	7%	17%	17%
Empowering attitudes	7%	7%	7%
Data and evidence	7%	7%	6%
Habilitation and rehabilitation	4%	3%	0%

Accessibility standards	7%	3%	2%
Access to justice	-	-	2%

Examples of outcomes reported include a needs assessment, baseline studies or legal review, multi-partner discussions or workshops, training, communications or promotional campaigns, and new disability guidelines. These data resemble a more traditional, metrics-based summary of project activities and ceased after 2016.

The Connections (UNPRPD, 2016) and Intersections (UNPRPD, 2018) reports list metrics from various country projects to highlight programmatic impact. For example, awareness-raising efforts for universal design in Ukraine reached 3.5 million people from their Round 1 (R1) project, 4,500 children with disabilities entered a mainstream school environment in Moldova (UNDP, 2016), or projected impacts such as 10.7 million “people with severe disabilities likely to benefit from supported employment in China” (UNPRPD Technical Secretariat, 2018, p. 16). Baseline data nor calculations were included. Large impacts such as the metrics listed show broad progress around the world but lack the supporting evidence to understand them from a structural perspective. Quantitative measures are common in development and useful for tracking large datasets over time, however, these metrics represent frequency or percent of spend and provide little insight into the programmatic impact or process behind outcome-level transformations that were (or were not) achieved. In looking at the reporting trends toward programmatic quality, outcome and experiences cited by many academics and practitioners above, the field of disability-inclusive development calls for the story behind the metrics.

Impressive advances were reported qualitatively across all projects in the annual reports, which provided short summaries of select country projects and their milestones from the

preceding calendar year. For example, in 2017, Moldova reported outcomes including the participation of Organisations of Persons with Disabilities (OPDs) in working sessions with the First Deputy Prime Minister of Social Affairs, the creation of a consultative body under the Ombudsman's Office, and amendment to the Civil Code removing an automatic guardianship over all persons with intellectual or psychosocial disabilities were reported (MPTF, 2017, p. 8). In 2018, the Multi-Partner Trust Fund (MPTF) report highlighted several milestones from the country project in Serbia, including legal analyses, reviews and amendment drafts. In Uganda, the project assisted in developing inclusive education materials using technology and provided feedback and support in the development of guidelines for accessible publications (MPTF, 2016). While there are reported developments and progress towards inclusion, there is little detail about how this happened, how OPDs or persons with disabilities were involved and to what extent, or contextual barriers that remain.

While the reports were released annually, a story unfolded when synthesised by country over the years available in the data. In 2015, the UNPRPD report shared outcomes from Tajikistan's first round of funding, stating: "Recommendations for strengthening the Governmental Working Group on the CRPD (GWCRPD) Action Plan were developed with UNPRPD technical support and submitted. (MPTF, p. 10)" The narrative provides context to the role of the UNCT in the actionable step toward the government adopting the CRPD. The following 2016 report continued,

"Furthermore, H.E. Mr. Rustam Shohmurod, Minister of Justice of Tajikistan recently highlighted while speaking at the UPR meeting in Geneva in May 2016 that Tajikistan is now ready to sign the UNCRPD". (p. 9)

The UNPRPD prepared a report on implications of signing the CPRD, a government-hosted roundtable and workshop, advocacy, financial analysis and other activities to progress the government toward signing the CPRD, which provided a list of project deliverables to advance towards the target outcome. The narrative section of the 2017 report did not have a dedicated section on the progress in Tajikistan, however, the following year announced:

“22 March 2018, in a landmark step, the President of the Republic of Tajikistan signed the CRPD after 4 years of intense advocacy, consultations and technical analysis supported through the UNPRPD project. (2018, p. 11)”

The project began in 2014 and provided annual updates until formal signature in 2018 (with the exception of 2017), four years after the project inception. While the data show incremental progress, details on how the other key partnership, civil society, played a role in progress milestones or final signature are not captured in detail. If another country or advocacy organisation were looking to engage government to sign the CRPD, this report would provide a sense of the activities taken by the UNPRPD project in Tajikistan, but little insight into how to approach, initiate or align stakeholders to the listed activities, what makes them meaningful, their impact or why they were chosen as activities to result in signing the CRPD.

Each report provided updates in the annex, listing targeted deliverables designed to reach the overall project outcomes. Some progress updates provided concrete outcomes, such as in the project in Armenia:

“A technical commission responsible for monitoring of implementation and efficiency of measures for provision of prosthetic and orthopedic devices, rehabilitation and other technical support included in the rehabilitation plans was established in 2015. In 2015,



the total number of assistive products provided was 338. In 2016, 3,115 assistive devices were provided to women and men with disabilities representing a more than 900 percent increase in the provision of assistive devices. “(2016, p. 31)

All projects had multiple workstreams, some of which were more structural and others more immediate. Armenia, for example, sought to implement a new disability determination system for structural impact alongside the example of increasing assistive devices above. The reports provide programmatic updates, such as when new rounds of funding initiate project activities, milestones and metrics, rather than the processes behind them. Taking the example of assistive devices in Armenia cited above, was the result a one-time investment because of the UNPRPD project, or will the provision of devices continue? How structural was it? Did the devices reduce barriers facing persons with disabilities, and if so, how? And how did the UNPRPD strategic and operational approach drive alignment to invest in a 900% increase? The process and experiences of all stakeholders, particularly the role and participation of persons with disabilities and their representative organisations, would add to the available data and provide an understanding of structural change as a result of the UNPRPD.

It is worth noting that the reports did not provide a section reflecting on challenges, limitations or how the UNPRPD iterates over time, however some internal changes can be inferred, such as the addition of dedicated project fund in 2018, stating,

“Building on experiences of the first two funding rounds, for the first time, UNPRPD projects received dedicated funding to support project inception activities to plan project implementation, organize joint vision building workshops and training for multi-stakeholder groups on the CRPD, in particular, on CRPD compliance “(MPTF, 2018, p. 5).

The opening statement suggests an effort to improve on known challenges, however, the details of their learnings or what prompted the change are not listed in depth.

### 3.1.3 Understanding programmatic implementation

van Veen, Bunders & Regeer (2013) argue the need for co-creation of knowledge in disability inclusive development, with multiple stakeholders providing input across sectors. Further, Asada et al note, “While structural changes are not new, most studies in literature do not explicitly report on or do not employ theoretical frameworks to guide evaluation” (2019, p. 377). With most of the evidence produced from the perspective of the UNPRPD and through outputs and deliverables, there is need for external and peer-reviewed studies which include the points of view of partnering stakeholders in line with the programmatic ToC.

The gap between formal alignment with international frameworks and practical implementation is broadly referenced (Donald & Speck, 2020; Kosar & Petrov, 2018; Gadda et al, 2019; Cole,2015), and not exclusive to disability-inclusive development or challenges in realising the CRPD. Donald & Speck (2020) compared the implementation progress between similar judgements across 3 European countries and determined factors such as mounting pressure on government parties, political commitment, and long implementation trajectories in triggering structural change. Murray & De Vos (2020) note the complexity of a ‘government partner’ to include a wide range of state actors, even within a single ministry, for the practical implementation of human rights. Further, they recognise the ambiguity around who will be responsible and what processes will be followed for the implementation activities required for national adoption, beyond engagement and political alignment. Similar findings emerged in a study by Chenaf-Nicet (2020) looking at factors that impede or facilitate structural change more broadly in Sub-Saharan African countries, citing the quality of institutions as a predictor of

durable development. Most literature cites broad categories of inequality targeted for structural interventions, such as education, employment and health, and the need for more research to evidence change.

Available reports on the UNPRPD projects largely focus on the perspective of decision-makers without direct reference to power differentials or redistribution in capacity-building and leadership during the development process, despite being a key construct in theoretical frameworks across social science disciplines (Wescott et al, 2021a; Wescott et al, 2024). Importantly, there remains a gap in transparent systematic research to understand the process, limitations and evidence on structural changes from the perspective of all partnering stakeholders. The existing evidence highlights the need for deeper exploration of institutional relationships found in the UNPRPD partnership approach between UN agencies, government and civil society to structural change, challenges to implementing human rights, and need to identify facilitators and barriers to disability-inclusive development. The UNPRPD as a programme that sought structural change presented an ideal vehicle to study these processes.

## 3.2 Background

### 3.2.1 International recognition

The CRPD and Optional Protocol were adopted December 13, 2006, and came into full effect two years after. The Optional Protocol recognizes the Committee to the Rights of Persons with Disabilities (CRPD Committee) as a mechanism for an individual or group to file a complaint if there are violations to the Convention, ensuring the values of the treaty are addressed in a substantial way (UNDG, 2011). Countries sign the Convention and Optional Protocol before ratification or directly accede, which binds the treaty and obligates State Parties to full implementation of the CRPD and reporting to the Committee (OHCHR, 2023). As of

2024, the Convention has 164 signatures, of which 94 have also adopted the Optional Protocol (United Nations Treaty Collection).

The Convention not only recognizes and legitimizes people with disabilities, it also displays 50 articles to outline human rights in a disability context through a legally binding treaty (United Nations, 2006). While disability crosscuts previously protected populations (Convention on the Rights of the Child, Convention on the Elimination of all Forms of Discrimination against Women), the CRPD addresses persistent discrimination in a way that strengthens all treaties by establishing inclusive principles and explicitly recognising disability in a way that had not previously been done (UNICEF, 2009). Following the CRPD, other UN instruments have aligned with the new model for disability, including the World Report on Disability in 2011 (World Bank) framing disability from the perspective of the International Classification of Functioning, Health and Disability (ICF). The ICF includes the social environment in the determination of disability, reinforcing the stance of the rights-based paradigm of the CRPD (See *Disability Models*). The Sustainable Development Goals (SDGs) (UN, 2011), specifically mentions disability in five of the 17 goals as compared to zero of the UN's previous Millennium Development Goals. Just as the CRPD strengthens previous human rights frameworks by documenting the application of those rights in a disability context, particularly as people with disabilities are known to be some of the hardest to reach (Kuper & Heydt, 2019), but it further unifies the network of UN sanctioned priorities across initiatives for disability inclusive development. In other words, it becomes more difficult to achieve success in one area of development such as the SDGs without attention to persons with disabilities, theoretically reducing historical failures that have left disability behind in development efforts.

### 3.2.2 Critiquing international frameworks

It is important to remember multiple instruments do not themselves ensure the implementation of disability rights or the success of stated goals. While the institutions are harmonized in their paradigm of disability and inclusive development, the expansion of human rights tools has been criticized for diluting the commitment. de Waal (2003, p. 254) states, “This proliferation of laws is a problem. Many are impractical. Some cannot realistically be implemented. Others have been signed by governments that do not have the capacity or the will to implement them. This is actually a sign of disrespect for the rule of law.” While not all frameworks with explicit mention of disability are human rights law, they are recent ideological changes on top of a system so complex as to become programmatically inefficient, or potentially impossible under current conditions. Evidence of this phenomenon exists in the near complete uptake of the CRPD, yet innovation and funding for disability inclusive development remain profoundly stagnant. de Waal appreciates the importance of developing and signing such instruments while posing reflection as to the reality of implementation in such tentacled obligations in under resourced and politically unstable countries.

The specific experience of marginalization and oppression facing persons with disabilities make the CRPD both an important paradigm shift in development and equally difficult to action within existing structures. Two popular disability paradigms highlight the complexity of implementing disability inclusion and help to explain the recent shift towards structural change rather than individual treatment fundamental to realising the CRPD.

### 3.2.3 Disability Models

Disability can be defined in many different ways based on stakeholders’ paradigms and interests and can lead to different outcomes when translated into development programming. Definitions of disability can also be confounded, often seen when an individual’s impairment is mistaken for

the social constructs of disability that surround individuals with an impairment. Exclusion can take on many forms and is both contextualized to the social environment, as well as a global phenomenon with shared attributes such as the topics outlined in the substantive articles of the Convention (e.g., education, employment, right to life). Disability models are commonly referenced either in a binary between the social/rights and deficit models or rooted in historical and cultural constructs such as charity or religious (Cobley, 2018). The rights-based model of the CRPD shares definitional aspects with the social model, whereby the connective tissue lies within the target for intervention: the social environment rather than the person with a disability. This research explores how stakeholders originating from different disability paradigms converge to implement rights enshrined in the Convention on the Rights of Persons with Disabilities (CRPD, the Convention), from a disability rights perspective.

A paradigm's influence on an intervention is important. Countries that have signed and ratified the CRPD may allocate more funding and effort to education for children with disabilities, which is outlined in Article 24 of the Convention. While the state may be putting action to their commitment, it does not ensure compliance. For example, a state can use those funds to build institutions where children are segregated. In this way, development efforts in various sectors mandated by the Convention must also be aligned in the actual implementation. To align planned activities in development, disability rights and stakeholders' paradigms must be understood.

There are two main paradigms that function as both a definition of disability, as well as a model for understanding the implications of disability in context. The first considers disability as a deficit or problem strictly within and concerning the individual (Marks, 1997; Levitt, 2017; Winance, 2016). This paradigm has been coined as *the medical model*, as the attempts to address

disability have largely been ‘cure’ oriented (Marks, 1997; Levitt, 2017; Winance, 2016). The medicalization of disability is only part of the lens. Terminology such as ‘wheelchair-bound’ or ‘hearing impaired’ inextricably link the person to notions of limitation and are often used to label or define people and groups. Exclusion of people with disabilities may be addressed by making the body ‘normal’ (homogeneous, or able bodied), conforming the individual to narrow and relatively fixed social norms.

Disability and social inclusion literature highlights the urgent need to shift away from the medical model, and into what is called *the social/rights model* of disability. It is important to clarify the distinct characteristics resulting in harmful practice, as medicine and individual interventions are not wholly problematic. Medical prosthetics or hearing aids are indeed adjustments to better fit a person in their social environment, however recognition of devices as *assistive* rather than curative- or assimilative- are the crux of the paradigm shift.

An alternative approach to disability is *the social model*. While the previous lens saw the problem within the individual, the social model recognizes the problem external to the individual, and relational to the environment (Marks, 1997; Levitt, 2017; Winance, 2016). Aspects of the environment (also known as *structures*) were built for some bodies to participate, but not all (Power, Lord, & deFranco, 2013). The classic example is a wheelchair user crossing a street without a curb cut. This model of disability aims to suggest the sidewalk curb is prohibiting the individual from crossing the street, rather than the capacity of the person with a mobility impairment. Had that curb cut been installed, the individual would have full access to cross the street. A sidewalk design is easy to recognize and requires a straightforward solution, while others are more abstract, such as barriers in policy or education practices. Development action must bear in mind ‘environmental’ barriers are not necessarily tangible structures around

us, but also abstract structures comprised of networks, attitudes, beliefs, and larger social systems.

### 3.3 Theoretical background

The UNPRPD indicated several factors considered central in facilitating structural change, shown in Table 3 (UNDP, 2016). Many of these have a clear social science and interdisciplinary focus: from cultural norms to inclusive organizations, and the use and development of disability relevant data.

**Table 3:** Factors Central in Facilitating Structural Change

<b>Enabling factor</b>	<b>Thematic priority</b>
<b>Enabling legislation and policy frameworks</b>	Promote the ratification of the CRPD whenever relevant, and the development (or reform) of legislation and policies (disability-specific and not) as well as strategies and action plans
<b>Empowering cultural norms</b>	Reverse stigma, prejudices and negative stereotypes while promoting supportive and empowering attitudes
<b>Access to services (mainstream and targeted)</b>	Enhance access to mainstream as well as targeted services by improving their design and delivery modalities, and by promoting measures that will increase availability and affordability
<b>Access to justice</b>	Increase access to justice for persons with disabilities and the capacity of the justice sector to appropriately respond to the specific circumstances of persons with disabilities



<b>Application of accessibility standards</b>	Promote the application of accessibility standards to products, environments and processes, including non disability-specific interventions undertaken by development partners
<b>Adequate Access to rehabilitation, habilitation including assistive technology</b>	Improve access to rehabilitation and habilitation – including assistive technology – by strengthening the availability and affordability of services and improving the design of assistive technologies
<b>Adequate data and evidence</b>	Improve disability-specific data and support research on different aspects of disability as well as the codification of evidence

The UNPRPD approach focuses on various factors, such as multiple perspectives on disability in both local and global constructs, international development, aid and stakeholder relationships, and the participation of persons with disabilities and their representative organizations in the planning and provision of services (Huang & Burchardt, 2019; United Nations, n.d.). Although the UN and international frameworks provide a compass and metrics for progress, there may be differences in perspectives between planners and service providers, resulting in new approaches to development projects (Marrone & Mitchell, 2020). However, the novel approaches to development that include disability have not been widely studied or validated at the national or global scale, particularly in highly contextualized, cross-cutting projects (Huang & Burchardt, 2019; United Nations, n.d.).

Several foundational theorists have worked to explain structures, individuals and change to the social environment and can help situate the UNPRPD programmatic approach. Karl Marx

understood individuals in opposing and conflicting groups based on the possession of economic capital resources (Marx, 1992). According to his theories, stratification between classes of people is hierarchical and relational- those with wealth and those without. Further, each of those classifications have their own cultures and operate within a shared social field. Emile Durkheim (1993, Giddens, 1971) developed a sociological lens, creating theories of the underlying forces groups exert on their membership. Max Weber brought forth nuance to the relationship between power and how it manages social order, as well as intangible capital such as status (Giddens, 1971; Weber, 1946). Weber saw change and processes within social systems in a feedback loop with/between agents in power. The individual contains social power, tethering them to structures. His contribution was highly interpretive and grounded relationally, depending on the perspective of a given individual. All of these early theorists uphold the idea that society is constructed rather than inherently natural or determined.

Social order and their underlying forces often organize into hierarchies in which some groups are dominant, and others subordinate. Social dominance theory (SDT) is more recent than the work of founding theorists, emerging in 1992 (Sidanius et al). SDT takes the classes or groups of people, forces behind them and explores the historical tendency for societies to arrange in an unequal way based on group characteristics (Sidanius et al, 1992). SDT goes further to theorise how inequality and dominance are maintained through legitimizing myths, or cultural ideas strong and widespread enough to either legitimize one group or delegitimize another, resulting in meaningful resource divisions (Sidanius et al, 1992). Race, gender, and disability have been subject to delegitimization based on cultural myths so pervasive as to become status quo, to name a few.

Myths are constructed and vary by culture. The dominant myths are not unwielded and alone in social ideology, albeit they do hold tremendous power, and thus, often oversaturate opposing myths. Myths that uphold the existing dominant understanding of ‘othered’ groups are considered hierarchy-enhancing, according to SDT (Pratto & Steward, 2012). For example, the myth that persons with disabilities are noncontributors to society, such as the notion that an intellectual disability is a complete lack of intellect. Or surprise when persons with physical impairments are physically capable of many things. These sweeping myths show up in social environments built by dominant groups that perpetuate and reinforce ablest ideology when, for example, persons with spinal cord injury cannot in fact participate in the workplace if they are in inaccessible buildings. Myths become legitimized. Alternatively, hierarchy-attenuating myths offer another explanation for such beliefs. One example is the rise of the social and rights-based model of disability, advocating for a paradigm shift in the dominant myths of disability. Sidanius et al (1992) build on the social construction of group classifications in a shared social field and provide a framework for understanding the distribution of ideologies that preserve inequality in social systems around the world.

Structures and groups are important to distinguish from their surrounding field. Rami (2018, p. 8) recognizes the difference between the field of humanitarianism, humanitarian organisations conceptualizing programmes and processes, and humanitarians implementing the work- all associated with creating intentional change. A similar definition is crucial for proper analysis of disability inclusive development. The field of development differs from implementing organisations like the UN and the individuals working within them. Formative theorists provide a preliminary connection between fields, structures and agents; however, the relationship is directly conveyed in Pierre Bourdieu’s theories.

### 3.3.1 Pierre Bourdieu

Like the other theorists mentioned above, the concept of field is an important container for applying Bourdieu's concepts. According to Bourdieu, fields are numerous, hierarchical and overlapping, each containing their own mini logics and practices (Bourdieu, 1977). For example, the field of disability inclusive development interacts with an established field of international development. One is borne of the other, more established arena, bringing with it the same structures, laws, knowledge, exchanges and sometimes even actors. While fields are constructed by social groups, they are objective in the sense of creating a social reality. People experience real barriers to education, healthcare or social mobility for reasons that were largely determined before any individual interacted in that field. They become durable over time and difficult to change.

Fields contain social structures that are also nested and positioned based on capital. For example, the object of study in this research is the UNPRPD, which works to assist member states to progressively implement the CRPD through country project support. In studying the UNPRPD programme, it can seem as if it is an isolated subject. This would reduce the analysis to assume the UNPRPD was operationally independent from the overarching structural affiliation- the United Nations system. The UNPRPD is not an isolated initiative. Many of the UN representatives have previously and currently worked in projects outside of the scope of the UNPRPD, and they bring their experiences with them. Much like Lewin's concept of 'life space' which defines an individual's experiences and opportunities as a reflection of environmental, historical and social phenomena unique to each person (Lewin, 1936), Bourdieu defines this embodiment of structural membership as habitus, or the culminating dispositions ingrained from an individual's social experiences. Importantly, not all experiences and structures are created equal. Some have more or diverse resources valuable to a social system, known as capital.

Capital resources are the forces that determine the power and influence possible to exert on a social system. While Marx focused on economic capital and Weber on status, Bourdieu identified two additional primary forms of capital. The first is social, or interpersonal networks- knowing the right people. While this concept is now commonplace and integrated into professional life through networking events, internships and conferences, Bourdieu's work brought social networks into light as a form of power (Bourdieu, 1986). Finally, cultural capital is distinguished into three categories. Cultural capital is a form of legitimacy found in objects (objectified), experiences (embodied) and formal process (institutionalized) which hold meaning and convey a social status (Bourdieu, 1986). For example, graduate degrees, stamps in a passport or diamond engagement rings all act as social resources. Unsurprisingly, disability has been systematically withheld from durable capital possession. Objects such as assistive technology and their counterparts- such as stairs or inaccessible computer programmes, have significant meaning. While that meaning may be different for one group to another (wheelchair users feeling freedom of mobility from chairs versus ableist ideas of 'wheelchair bound'), much like SDT shows, the dominant myth is difficult to counter.

Expanding on Sidanius et al, legitimizing myths are concerned with worldviews. Bourdieu also explored frames of reference in the concept of doxa (Bourdieu, 1977). Individuals are informed by their social participation and environment where much is out of purview. Some of this is by design with segregation or the results of historical exclusion. Doxa is much like habitus or 'life space' at the group level. Groups are informed by their position in a field, the capital resources available and historical status, which lead to norms and beliefs within a given group. While these doxa norms are constructed and reproduced over time, they are often

assumed to be natural or given- the way the world is. Much like hierarchy-enhancing myths, doxa and the construction of social spaces reinforce norms to appear universal.

Another important rationale for the application of Bourdieusian theory and analysis is the fundamental cohesion between the ontology and epistemology, and key features of the social model of disability to which development aims to mainstream. Bourdieu's theories of structural change come from a non-dualistic ontological perspective. Rather than the dichotomy of realism or relativism, Bourdieusian theory recognizes the subjective construction of objective realities (Grenfell & Lebaron, 2014; Maton, 2003). Disability exclusion is not the product of an inherent lack of individual value or purely subjective experiences, rather it is constructed through a number of structural interactions over time (Byrne, 2007; Wescott et al, 2021).

Finally, Bourdieu noticed there are times when doxa can be at odds with an individual's habitus. For example, social changes may be rapid, challenging one's sense of normal. Confronting something new, such as a disability rights paradigm can lead people to question the world they once knew, resulting in tension and crisis of the self. He termed the disharmony between an individual and their surrounding doxa *hysteresis* (Hardy, 2014; Strand & Lizaardo, 2016). In efforts to create intentional change such as international development programming, particularly the introduction of something that has not been done before like disability inclusion, requires confrontation of doxa and adjustments to internal habitus, social norms and the structures that enforce them.

Disability development interventions from a rights-based model are not a direct transfer from exclusion to inclusion; rather, they disrupt the forces locking disabled people out of participation in the capital accumulation and exchanges that produce social conditions. Bourdieu's theories and methodology address systems of inequality through the forces driving

structural composition, recognising power concentrations in a field resulting from the accumulation or withholding of resources over time (Bourdieu, 1987, Edgerton & Roberts, 2014; Hilgers, & Mangez, 2015; Topper, 2001). When applied to the UNPRPD initiative, this methodology explores how establishing partnerships between structures and resource redistribution can initiate more inclusive societies. If social systems are situated based on the relationships between structures as Bourdieu described (Bourdieu, 1987; Bourdieu, 1990), then the aim of inclusion is to reduce the separation between disability and influential entities that determine their participation (e.g., accessible education, employment, etc). While the barriers to inclusion are embedded in an interconnected network of structures, studying the response to interventions between structures can assist in determining if the desired outcomes of increased social participation are being achieved (Wescott et al., 2021). Documenting these responses to development efforts helps to unveil the process of structural change and capture many of the underlying attitudinal and paradigm shifts as a result of local UNPRPD country projects.

Intentional disruption attempts to develop new societal norms and institutionalise them into everyday practice. Structural change, such as the UNPRPD country projects targeting disability exclusion, triggers a reform to what is normal (*doxa*), and is embodied (*habitus*) through the individuals subject to what Bourdieu called the new ‘rules of the game’ (Bourdieu 1990, Wescott et al., 2021). Theoretically, if new norms reflecting the CRPD are implemented at the national level and seen in social practice, over time the rights of persons with disabilities will be so common as to be assumed true or natural, and thus the Convention will be realized. With this premise of intentional change and practice from key, powerful actors in society, changes considered most significant by participants because of the UNPRPD country projects were

explored to more deeply understand structural change toward achieving the broader development goals of disability inclusion.

### 3.3.2 Theory of Change (ToC)

Theories of Change have evolved from the early social and organisational psychology of Kurt Lewin, and in particular his conceptualisation of Force Field Analysis (Lewin, 1943) to become a major framework for project delivery across many domains (DeSilva, et al., 2014; Breuer, 2016), and increasingly so in the international aid and development work context. ToC is a theory-based approach to planning, implementing, or evaluating change at any level (individual, organisational or community). The assumption is made that an action is purposeful. It articulates explicitly how an initiative is intended to achieve outcomes through actions, while considering its context (Ling & Todd, 2015). Thus, it is the result of a series of critical thinking exercises that aim to provide detailed understanding of the immediate and mid-term changes required for a particular community to achieve a long-term goal (Harris, 2005). ToC is a fundamentally participatory process, involving active engagement by key stakeholders (Taplin & Clark, 2012). Participants articulate their long-term goals, identify the actions that they believe are required for the achievement of these goals, and identify which actions each participant will take responsibility for producing (Harris, 2005). Connell & Kubisch (1998) have noted that high quality ToCs have three defining characteristics: plausibility (evidence and common sense suggest that activities will lead to desired outcomes); feasibility (economic, technical, political, institutional, and human resources will be available to carry out the initiative); and testability (it is specific and complete enough for an evaluator to track its progress in credible and useful ways). These three qualities help to ensure that a ToC can realistically affect change in a particular setting.



ToC is distinct from sociological or psychological theories, which describe why change occurs, although these may be used to inform the ToC (De Silva et al. 2014). De Silva et al. (2014) have illustrated how ToC can aid the development of interventions by providing a framework for enhanced stakeholder engagement and by explicitly designing an intervention that is embedded in the local context. They have noted that “ToC enables the systematic identification of knowledge gaps to generate research questions that strengthen intervention design” (De Silva et al., 2014, p. 1). Breuer et al. (2016) have stressed that it is important to strengthen the body of literature regarding the practical application of ToC to develop our understanding of the benefits and advantages of ToC. The current paper reports such an application.

A ToC provides a framework for realistic and flexible planning by applying critical thinking to the design, implementation, and evaluation of programmes intended to instigate change in a specific context (Vogel, 2012). Fundamentally, ToCs focus on how an intervention will work, rather than whether an intervention will work (Rogers, 2014). ToC is useful both as a planning tool and for carrying out monitoring and evaluation (Taplin & Clark, 2012). A ToC can be used to develop a project plan in advance, and this can in turn be used as a reference point for evaluation of the project (Rogers, 2014). During the development stage, outcomes are explicitly defined, and each outcome is assigned one or more specific indicators of success, which can then be assessed as implementation proceeds (Taplin & Clark, 2012). ToCs can also be used to evaluate projects that were developed without an initial ToC, whereby a ToC identifies the specific goals of the project and links these goals to interventions within the project (Taplin & Clark, 2012). Additionally, ToCs can be revised over time as necessary (Connell & Kubisch, 1998). This aspect of ToCs is particularly important in international development, as it allows for

realistic implementation of interventions through an inherent acknowledgement that reality often necessitates adjustments to initial action plans. However, the overarching emphasis in ToCs on identifying long terms goals ensures that any needed revisions to ToC will align with an intervention's ultimate desired change.

The identification of rationales and assumptions is a crucial aspect of the development of a ToC (Vogel, 2012). Rationales explain the logic between each causal relationship along the pathway in a ToC, and assumptions explain the contextual background to a theory as well as the justification for the chosen theory (Taplin & Clark, 2012). Specifically, assumptions identify the strategic advantage of a ToC over alternative theories that might be contextually appropriate (Church & Rogers, 2006). Identifying assumptions is particularly important in international development, because it can help to clarify whether the activities and outputs of a ToC are appropriate for influencing change in the specific context in which it is being carried out (Vogel, 2012). Ideally, rationales and assumptions are supported by social science theory and research-based evidence (Stein & Valters, 2012). This can strengthen both the plausibility and the feasibility of a ToC, thereby increasing the likelihood that its stated goals can be realistically achieved (Taplin & Clark, 2012).

Due to the suitability of ToC for results-based planning for international development, it is used increasingly by a wide range of development actors, including governmental agencies, bilateral donors, civil society organisations, and international non-governmental organisations (Vogel, 2012). The publications in this PhD offer new considerations for disability inclusive development contexts with case studies to better understand how the UNPRPD ToC is used in practice.

### 3.4 Purpose of the study

Given the mandate for countries to realise disability rights enshrined in the CRPD and the novel initiative introduced by the UNPRPD, this research provided the opportunity to understand the United Nation's approach to intentionally activating change at the theoretical, programmatic and country levels with the research question, *Has the UNPRPD programme triggered structural change, and if so, how?*

This research will provide several contributions, including evidence-based insights into the UNPRPD programmatic processes significant to realising disabilities rights across country contexts, a deeper theoretical and practical understanding of structural change in disability inclusive development, and a multistakeholder perspective as stated in the UNPRPD ToC. The research is interdisciplinary drawing on sociology, psychology, demographic studies, international development, law and policy, and implementation science. Each publication in this study looks at the research question from a particular level of inquiry or country application. Beginning with theory to frame the research perspective and a global analysis of initiatives within the UNPRPD programme, a project-level analysis against other UN frameworks, followed by two country projects selected for in-depth inquiry and analysed through theoretical framework established in the first publication. The next section describes the research designs used across publications.

#### 3.4.1 Research design

The UNPRPD is a relatively new joint UN programme, established in 2011 (launched in 2012; UNDP, 2016). As of 2019 (when this research began), scholars had not conducted any peer-reviewed studies of the programme. Many of these country projects represented a state's first large-scale disability rights initiative, meaning no standards were in place to measure with

quantitative tools, including how to determine or define disability, for example. The variation and novel quality of projects required an open exploration, facilitated by a combination of research methods, to better understand the UNPRPD programmatic ToC in action as a starting point.

**Table 4:** Research design by publication (See publications in Appendix)

Publication	Methodology	Methods
<p>Wescott, H., MacLachlan, M., &amp; Mannan, H. (2021). The macropsychology of disability rights and structural change: Using Bourdieusian analysis to understand stakeholder power relations. In M. MacLachlan, &amp; J. McVeigh (Eds.), <i>Macropsychology: A population science for Sustainable Development Goals</i> (pp. 175-187). Springer.</p>	Qualitative	<p>Inductive literature search</p> <ul style="list-style-type: none"> <li>• Theoretical development</li> </ul>
<p>Wescott, H. N., MacLachlan, M. and Mannan, H. (2021).</p>	Mixed methods	<p>Desk review</p> <p>Statistical analysis</p>

<p>Disability Inclusion and Global Development: A Preliminary Analysis of the United Nations Partnership on the Rights of Persons with Disabilities programme within the context of the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals. <i>Disability, CBR &amp; Inclusive Development</i>, 31(4), 90–115.</p> <p><a href="https://doi.org/http://doi.org/10.47985/dcidj.397">https://doi.org/http://doi.org/10.47985/dcidj.397</a></p>		
<p>Wescott, H., &amp; MacLachlan, M. (2021). Implementing ‘real’ change: A Bourdieusian take on stakeholder reflections from the United Nations Partnership on the Rights of Persons with Disabilities project in</p>	<p>Mixed Methods</p>	<ul style="list-style-type: none"> <li>• Semi-structured interviews <ul style="list-style-type: none"> <li>○ Analysis: IPA</li> </ul> </li> <li>• 2011 Uruguayan Census data <ul style="list-style-type: none"> <li>○ GIS: Hotspot analysis</li> </ul> </li> </ul>

<p>Uruguay. <i>SN Social Sciences</i>, 1(12), 282. <a href="https://doi.org/10.1007/s43545-021-00280-w">https://doi.org/10.1007/s43545-021-00280-w</a></p>		
<p>Wescott, H., Credit, K., Tatic, D., Lorell, C., &amp; MacLachlan, M. (In press, 2023). Full and Meaningful Participation: Considerations for Engaging Persons with Disabilities in Development Projects. In M. Meyers, McCloskey, M. &amp; Petri, G. (Ed.), <i>Hierarchies of Disability Human Rights</i>. Routledge.</p>	<p>Qualitative</p>	<p>Semi-structured interviews</p> <ul style="list-style-type: none"> <li>• Analysis: IPA</li> </ul>
<p>Wescott, H., Ferri, D., &amp; MacLachlan, M. (2023). Participation, legal capacity and gender: Reflections from the United Nations Partnership on the Rights of Persons with Disabilities</p>	<p>Qualitative</p>	<p>Semi-structured interviews</p> <ul style="list-style-type: none"> <li>• Analysis: IPA</li> </ul>

<p>project in Serbia Disabilities. <i>Disabilities.</i></p>		
<p>Wescott, H., MacLachlan, M., &amp; Mannan, H. (In press). The use of a Theory of Change to promote knowledge management and global implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In M. MacLachlan, I. Ebuenyi &amp; B. Kelly (Eds.), <i>Human Rights and Wrongs in Psychology and Psychiatry</i>. Oxford University Press.</p>	<p>Qualitative</p>	<p>Interactive working group Desk Analysis</p>
<p>*Smith, E., Huff, S., Wescott, H., Daniel, R., Ebuenyi, I. D., O'Donnell, J., Maalin, M., Zhang, W., Khasnabis, C., &amp; MacLachlan, M. (2022). Assistive technologies are</p>	<p>Qualitative</p>	<p>Inductive literature search</p>

<p>central to the realization of the Convention on the Rights of Persons with Disabilities.</p> <p>Disability and Rehabilitation: Assistive Technology, DOI: <a href="https://doi.org/10.1080/17483107.2022.2099987">10.1080/17483107.2022.2099987</a></p> <p>*While this paper is complimentary to the focus of this thesis it is not included in it.</p>		
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Each publication provides details on the specific methods used for each study. Of the data collected directly for this study, case studies were used to explore country projects in Uruguay and Serbia.

For country case studies, semi-structured interviews and on-site engagement with individuals from a range of stakeholders provided a standardised research tool for questioning while allowing the participants more freedom to share aspects of their experience that could not be anticipated in a structured questionnaire. While interviews were designed to use a semi-structured approach prior to data collection, once onsite, the participants' responses reinforced the need for flexibility. The same research design and set of questions were used in a single case study of the UNPRPD Armenia country project for my master's level dissertation, in which participants had no problem answering each question (Wescott, 2017). In the cases of Uruguay and Serbia, some participants answered each question, but many hesitated or declined to answer



specific questions. The same research design, applied to the same UNPRPD programme, resulted in different responses across country projects. Instead of compelling participants to provide an answer to specific questions, the semi-structured interviews allowed the flexibility to invite participants to share their experiences according to their feelings on the importance of the information. This approach maintained the integrity of researching a phenomenological event that is not yet well understood. It enabled the participants to be the experts of the subject under study, rather than limiting the contribution of each participant. Lastly, the approval to visit two country sites to conduct research made it possible to gain rich insights into different processes driving structural change towards implementation of the CRPD. Access to the UNPRPD also provided a unique opportunity to explore perspectives in depth in each country beyond quantitative measures.

This research was piloted with 11 representatives from the second round of UNPRPD country projects. Participants were interviewed at a knowledge management and quality assurance training programme (KnowUNPRPD) held at Trinity College Dublin in the Centre for Global Health in 2017 and was followed up with a full postgraduate country project case study in Armenia. The research question guided the questionnaire development and testing process, stating: *Has the UNPRPD programme triggered structural change, and if so, how?* Following the pilot and Armenia case study, countries were selected from the following KnowUNPRPD participant group held at Maynooth University in 2018, consisting of 18 country projects from the third round of funding support. None of the initial pilot participants were reselected for this PhD study.

### 3.4.2 Country selection

Site selection was a collaborative process between the primary investigator (PI; Holly Wescott), PhD supervisor (Prof. Mac MacLachlan), UNPRPD Technical Secretariats (Sreerupa Mitra and Natalia Mattioli) and United Nations Country Team (UNCT) representatives in the KnowUNPRPD training. Projects appropriate for study were evaluated by several criteria, including the following factors:

- How far underway the project would be during the research period (for example, some countries would begin programming during the site visit timeline, while others were well underway),
- Availability of partnering stakeholders in the country,
- Regional distribution,
- Country project objectives ranging across the CRPD articles.

UNCT representatives from Uruguay (Chiara Oriti Niosi, UNPRPD project coordinator) and Serbia (Rados Keravica, OHCHR) expressed interest in participating and were approved and selected for the research.

Uruguay and Serbia presented an opportunity to investigate similarities and differences between projects, including the targeted articles from the CRPD, the United Nations agencies involved, local needs and structural relationships engaged for programming. For example, both cases focused on CRPD Article 6 Women with disabilities and included UN Women for project implementation. These project targets varied in prominence: Uruguay's primary project intervention was aimed at women with disabilities and gender-based violence, whereas Article 6 was a smaller pillar of work, focusing primarily on baseline data assessment and pilot projects in

Serbia. Additional differences included duration and approach to Article 6 implementation. Similarly, the strength of relationships between stakeholders varied, allowing the research to look at issues of capacity, power differentials and engagement as they interacted with the project to drive structural change.

### 3.4.3 Participants

The three main UNPRPD stakeholder groups engaged in the study included UNCTs, local government and participating civil society organisations, particularly Organisations of Persons with Disabilities (OPDs; civil society for and by persons with disabilities). UNCTs oversaw the project and partnered with government ministries and civil society to collaborate on project development, planning and implementation. While the degree of participation varied across projects, all three groups were involved as key partners within the UNPRPD operational framework (UNDP, 2016). This research involved interviewing a sample from each of the UNPRPD key stakeholder groups: primarily individuals serving as focal points to the project on behalf of their institutions. An example from the postgraduate research conducted in Armenia, a subset of the Ministry of Labour and Social Affairs (MLSA) took part in the UNPRPD project. From those individuals involved (the target stakeholder population), five were interviewed (sample population) on behalf of their government affiliation, similar to their selection to represent the MLSA in the UNPRPD programming (Wescott, 2017). The same approach was true for civil society participation, where one individual was interviewed on behalf of the National Coalition OPD in the country, sampled from individuals in the UNPRPD project working group (Wescott, 2017).

**Table 5:** List of interview participants by country and stakeholder group

<b>Country</b>	<b>Partnering Entity</b>	<b>Number of participants</b>
<b>Uruguay</b>	United Nations	N = 6
	Civil Society	N = 2
	Government	N = 9
	Other (e.g., consultants, academics)	N = 5
<b>Serbia</b>	United Nations	N = 6
	Civil Society	N = 14
	Government	N = 4
	Other (e.g., consultants, academics)	N = 4

Sample size was determined by the number of participants engaged with the project in each country. Each project partnered with UN agencies, government ministries and civil society organisations relevant to the priorities set for implementation. Some projects had several ministries involved and one national disability organisation (or vice versa), varying the

distribution of partners in each stakeholder group. For the purposes of this research, gathering interview data from each of the three main stakeholder groups was essential. Because the sample was limited to the number of focal points on a given project, the aim was to conduct at least two interviews per stakeholder group in each country. Fortunately, the response in both countries was positive, and the number of interviews exceeded the desired sample size in both sites (22 total interviews in Uruguay and 28 in Serbia). The distribution of focal points per stakeholder group varied in each country; thus, some groups offered fewer individuals to select from for interviewing. Despite the variation in focal points per stakeholder group, all three institutions (UN, government and civil society) were represented in the interview data in both Uruguay and Serbia.

Participants were chosen based on purposive sampling, facilitated by the recommendations of UNPRPD country project representatives. The American Psychological Association (APA) has defined purposive sampling as “a sampling method that focuses on very specific characteristics of the units or individuals chosen. For example, a researcher investigating a specific type of amnesia may select for study only those individuals who have specific lesions in their brains” (APA, 2023). Resembling the APA definition, the selection of participants in this study concerned specific focal points to the UNPRPD project, rather than a random sample of individuals in participating government ministries. Likewise, participants were not randomly chosen from all civil society organisations or United Nations agencies in the country. Instead, participants were intentionally selected based on their affiliation with the UNPRPD project in Uruguay and Serbia. The sample selection was not limited to only two interviews per stakeholder, accepting any interested volunteer from all participating focal points of the projects. Once arriving in the country, the researcher and UNPRPD project coordinators worked

collaboratively to gather potential volunteer interviewees representing their UNPRPD country team, local government and partnering OPDs/civil society.

Inclusion criteria comprised the following:

- Referred by UNPRPD country project representatives,
- Involved with UNPRPD country projects in Serbia or Uruguay,
- Available during time of visit,
- Voluntary interest in participation.

Projects included a select number of people reflecting various intervention targets, creating a sample pool based on project participation. Therefore, individuals outside the UNPRPD project team fell into the research exclusion criteria.

#### 3.4.4 Participation of persons with disabilities

Some participants in this study were individuals with disabilities. Although ethics protocol traditionally defines persons with disabilities as vulnerable, this research made the following distinction: While some persons with disabilities are more vulnerable and require special consideration in ethics review procedures, recognising that not *all* persons with disabilities are vulnerable is essential to produce ethically inclusive research. Additionally, the study aimed to research individuals' experience with the UNPRPD project rather than the experience of any specific disability. Representatives of OPDs and other participating individuals with disabilities selected to partner with the UNPRPD project fit the inclusion criteria to participate in this study, having first been selected by the UNPRPD country team.

Realising that the United Nations system is an inaccessible system, as is reflected in programming, is vital. Of the 11 UNCT representatives in the 2017 KnowUNPRPD training (cohort for the postgraduate pilot study in Armenia), only 1 had any familiarity with disability (Wescott, 2017). Those involved in the more recent 2018 KnowUNPRPD training also had little experience in disability, with only one participant identifying as a disabled person. The people implementing disability inclusion were also subject to biases and paradigm shifting in the programmatic targets. Individual actors represented the structures undergoing change and were themselves a microcosm of the transformation intended in programming: in other words, the first stage of social restructuring. While the projects aimed to promote the meaningful participation of persons with disabilities, the projects originated from within an exclusive system. In this system, funding and awareness remained a barrier to UN internal operations, resulting in a limited subset of the larger disability umbrella that maintained an active role in projects. All participants involved in the UNPRPD projects were offered and provided reasonable adjustments to reduce barriers to participation in this study. As such, persons with disabilities were invited to share their perspective with all other government and UNCT partners.

Finally, as the interviews reached saturation in both cases, the researcher continued to collect data from any UNPRPD project focal point interested in participating. The sample population was established based on who the focal points brought into the project, and each contained a different institutional perspective. The invitation to participate was extended to all UNPRPD country project actors and remained open to anyone wishing to share their experience from that unique perspective. Fortunately, the research was well-received and featured a high level of participation, solidifying the thematic saturation.

### 3.5 Ethics

In the development of this doctoral dissertation, ethical considerations have been rigorously maintained, adhering to the comprehensive ethics procedures established by Maynooth University. The University's ethical framework emphasizes the protection of participant dignity and rights, which is paramount in the conduct of research involving human subjects.

#### 3.5.1 Informed consent

Central to the ethical integrity of the research was the implementation of the university's informed consent template, ensuring that all participants were fully aware and understanding of the nature, procedures, potential risks, and benefits of their involvement. Adherence to Maynooth University's ethical guidelines was crucial, particularly in guaranteeing that participants were not only informed but were also in agreement with the terms of their participation under conditions of voluntary engagement. This process was facilitated through the provision of detailed consent forms to all participants engaged at any point in the study that were clear and transparent about the objectives and implications of the research. Further, this research was submitted to the University Ethics Committee at Maynooth University and approved 9 November 2018, before data collection began. Once data collection commenced, each participant was introduced to the study's objectives, reviewed the informed consent in detail (available in English, Spanish and Serbian) and signed the university's consent form before interviewing the participant.

#### 3.5.2 Data protection

The General Data Protection Regulation (GDPR) was recently integrated into the European Economic Area (European Commission, 2017). Supervision guided data storage to adequately follow the best standard of protocol for this research. Based on European



Commission (2018) guidance, the only personal data collected were participant names, which were anonymised. This information is considered personal but not sensitive (European Commission, 2018), in compliance with the GDPR requirements. Moreover, data were only collected after participants gave consent. The safeguards detailed here comply with the data protection standard both within and outside the EEA, as advised by the European Commission (2017, 2018).

Participant names were processed through a random identification number generator to maintain the anonymity of the responses. As the research involved structural affiliation based on the UNPRPD programmatic framework, participant responses were identified in terms of their stakeholder group rather than name or title. No other identifiable information was necessary for this study.

### 3.6 PhD by publication: Overview

This study sought to better understand the processes leading to structural change based on two unique projects within the same UNPRPD programmatic framework. Context was vital to answering the research question, and the nature of the study was exploratory rather than bound by specific criteria or outputs. Based on the research question, a combination of theoretical analysis, secondary data analysis of existing material and primary data collection through qualitative, semi-structured interviews were the most appropriate approach for this study.

This section summarises each publication and draws common threads from the first two publications exploring theory and the overall programme as building blocks to frame the case studies, constructing a body of work to answer the research question. The next section states the implications of the research and recommendations for future inquiry. The chapter closes with a note of researcher reflexivity, efforts to reduce researcher bias, and limitations of the study.

### 3.6.1 Publications

- Appendix A: Wescott, H., MacLachlan, M., & Mannan, H. (2021). The macropsychology of disability rights and structural change: Using Bourdieusian analysis to understand stakeholder power relations. In M. MacLachlan, & J. McVeigh (Eds.), *Macropsychology: A population science for Sustainable Development Goals*, (pp. 175-187). Springer.

The first published chapter of the PhD identified a gap in the current literature between well-established theories such as by Lewin and Bourdieu, and more recent applied frameworks for project-based change. Lewin introduced ideas of initiating intentional change and Bourdieu offered theories of the forces operating behind the scenes, such as capital and the interconnectivity of ‘players’ involved in social systems. More recent ToCs focus on creating a construct for change by focusing on the intervention and key guiding elements. Each of these provide important aspects of how to understand what the UNPRPD programme sets out to do, however, several key elements such as interventions at a national scale and the nuances of disability exclusion are insufficiently supported in any of the existing literature.

This chapter sought to look at the existing theory and propose a new application from a macro perspective. It introduced key concepts that hallmark the findings in both subsequent case studies, such as field, capital and capacity. Stakeholders, or ‘players’, are highly sensitive and reactive to capital, both as they enter a new field with new players, but also in their exchanges- particularly if they counter the status quo. By mapping a baseline based on literature and evidence-based assumptions (e.g., OPDs have less economic capital than governments), it can be used as a tool for understanding how stakeholders enter the partnership, and how exchanges between UNPRPD partnerships can facilitate the realization of disability rights or reinforce existing norms. Capital can be used as an applied definition of capacity, or as Bourdieu describes the legitimacy of a structure (Bourdieu, 1984; Johnson, et al., 2006). This legitimacy is

dependent on who the other players are, their capital composition, and the essence of what makes them so powerful. Bourdieusian theory asserts relational capital is inherently psychological as it lives within the individuals that comprise stakeholder groups determining the systems that will, in turn, be cyclically internalised (Habitus). The chapter closes by reinforcing the need for theory and research to consider it.

- Appendix B: Wescott, H. N., MacLachlan, M. and Mannan, H. (2021). Disability Inclusion and Global Development: A Preliminary Analysis of the United Nations Partnership on the Rights of Persons with Disabilities programme within the context of the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals. *Disability, CBR & Inclusive Development*, 31(4), 90–115. <https://doi.org/http://doi.org/10.47985/dcidj.397>

Capacity and stakeholder position remained major themes across all publications. The case study methodology used to explore individual projects was an important approach to capture findings from diverse initiatives under a shared global programme, however, it was also important to first situate the UNPRPD programme against two other UN frameworks it sought to align with.

*Disability Inclusion and Global Development* analysed three rounds of project proposals accepted for UNPRPD funding against the cross-cutting and substantive Articles in the CRPD, as well as the SDGs. The analysis brought to light the strengths and limitations of the programme, and in particular, the capacity of the UN as technical experts. While the proposals rejected for funding were not observed in this study, the rights associated with a UN thematic Agency were strongly supported compared to those without a dedicated UN organisation. This in turn determines priorities in disability inclusive development and illustrates how UN agencies are powerfully positioned to transpose their mandate into the field of disability rights. The article

questions whether this project alignment to UN expertise counters the UNPRPD mission to support local needs, which was later identified as significant in the Serbia and Uruguay case studies.

The data also drew out a near complete absence of climate-related projects, which was worth noting as having emerged in the study for future consideration.

- Appendix C: Wescott, H., & MacLachlan, M. (2021). Implementing ‘real’ change: A Bourdieusian take on stakeholder reflections from the United Nations Partnership on the Rights of Persons with Disabilities project in Uruguay. *SN Social Sciences*, 1(12), 282. <https://doi.org/10.1007/s43545-021-00280-w>

Drawing from *The Macropsychology of Disability Rights and Structural Change* (2021), *Implementing ‘Real’ Change* (2021) applied the key concepts of Pierre Bourdieu and theoretical framing to the UNPRPD country project in Uruguay. The Most Significant Change Technique (MSCT) questionnaire was intended to be appreciative and generate reflection as to what worked from the project. Surprisingly, participants were largely unable or unwilling to answer the core question, and instead reflected on barriers and pain points. Given the unexpected response to a project using the same programmatic ToC and partnership framework as other countries selected for funding, the theoretical and macropsychological thinking previously published worked to understand the participants’ experiences with the UNPRPD project in Uruguay.

Important issues arose from the data around capacity and engagement, particularly between entities that hold very different positions in social space based on their capital composition. In Uruguay, the United Nations Country Team (UNCT) and government organisations felt the absence of persons with disabilities, and unsure how to find them. The two were highly intertwined with a common professional pipeline between the two, whereas

Organisations of Persons with Disabilities (OPDs) or representative civil society were ‘hidden’ from ever being identified. The Civil Society partner enlisted to participate in the project met some of the preferred criteria of the UNPRPD programme, however, they had no membership of persons with disabilities or operational staffing to engage at pace and par with the rest of the project.

Despite these challenges, the project participants embodied (cultural capital) the CRPD and the significance of having persons with disabilities and their representative organisations as key stakeholders, resulting in an internal estrangement from the project. The success of the project was perceived as dependent on uncontrollable outcomes such as national elections and the people who will occupy those positions of power. Overall, the individuals within the existing partnerships did experience change, however, it was not perceived as a ‘real’ result of the UNPRPD project.

- Appendix D: Wescott, H., Credit, K., Tatic, D., Lorell, C., & MacLachlan, M. (In press, 2024). Full and Meaningful Participation: Considerations for Engaging Persons with Disabilities in Development Projects. In M. Meyers, McCloskey, M. & Petri, G. (Ed.), *Hierarchies of Disability Human Rights*. Routledge.

The first Uruguayan publication focused more of the forces exerted on the project, and how they impacted the individual. There were additional process findings in the data and explored more deeply in the second publication from the same case study.

The chapter opens by grounding the reader in theory, with specific attention to hierarchies. Bourdieu describes how it really works when you have them, and Lewin provides a method for how to change things. Each one outlines a piece of the social landscape and how power is arranged in a case such as in Uruguay and was explored from that lens. The difference

in positionality between persons with disabilities, their representative organisations, and the other two partnerships were so vast as to leave the project team wondering, *where are they?* This rhetorical question uttered by multiple participants across the UNCT, and government organisations aligns with the theoretical understanding previously defined by capital, however the arrangement of capital was more clearly described as hierarchical as the partnerships were still relational from a Bourdieusian perspective, even in the absence of a civil society partner ready to align with the selected project priorities.

The inability to locate persons with disabilities warranted deeper investigation. The UNPRPD programme ToC outlines a tripartite partnership but provides little guidance on how to identify and engage the right partners. The 2017 Uruguayan Census included questions to identify persons with disabilities and was often cited in the project materials. That data was analysed geographically to find a statistically significant difference between where people with disabilities were located and the project activities. Thus, there was a theoretical and regional distance between stakeholders, aligned with some of the challenges participants described as they sought those critical partnerships.

The second half of the chapter provides an in-depth analysis of internal and external factors exerting force on the hierarchies found in the data such as how project priorities were selected, who has the power to determine what constitutes expertise, capital capacity, building partnerships and increasing structural stability. Despite these factors being identified as most significant by the research participants, they were not explicitly drawn out in the programmatic ToC.

- Appendix E: Wescott, H., Ferri, D., & MacLachlan, M. (2023). Participation, legal capacity and gender: Reflections from the United Nations Partnership on the Rights of Persons with Disabilities project in Serbia. *Disabilities*. 3(1),129-146.

This publication explored a second case study under the UNPRPD programme in Serbia. The project followed the same research methodology and analysis as the previous case study, as well as the programmatic ToC engaging the UN, government and civil society in a project to progress the rights of persons with disabilities in Serbia aligned with the CRPD. The project focused on legal capacity, women and girls, and though not featured in this publication, the right to employment. The findings note several important insights that reinforce themes from previous publications, such as the determination of project priorities based on local need, technical capacity of the UNCT and engagement of persons with disabilities. Stakeholder relationships between the UNCT and civil society were strong and participatory, outlining engagement as an ongoing process, both in advance of the project and beyond formal agreement to support the project.

In total, the five publications tell a story starting with the broadest conceptual analysis, then programmatic, then supported by specific cases to help answer the research question. Opening with a theoretical model to understand the UNPRPD programme, disability inclusion and exclusion, contextual factors across countries, stakeholder positions and structural change, the macropsychology chapter provided a framework for the articles that follow. The next study situated the UNPRPD programme against other global initiatives it sought to progress; the CRPD and SDGs. The analysis identified important patterns in the priorities selected for funding that mirror UN thematic agency specialisation, with limited pursuit of rights and goals outside of UNCT expertise, which arose as significant in both Uruguay and Serbia.

After exploring theory and the UNPRPD programme as a global initiative, the country project case studies followed, referencing the previous two publications to frame emergent insights. Participants responses explored different challenges in Uruguay and Serbia, however, partnerships, capital and capacity remained key concepts throughout the PhD.

- Appendix F: Wescott, H., MacLachlan, M., & Mannan, H. (In press). The use of a Theory of Change to promote knowledge management and global implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In M. MacLachlan, I. Ebuenyi & B. Kelly (Eds.), *Human Rights and Wrongs in Psychology and Psychiatry*. Oxford University Press.

UNCT representatives from the Round 2 UNPRPD programme attended a series of intensive Knowledge Management workshops over one-week in 2017, incorporating a range of social science concepts and methods, and resulted the development of a Global ToC for the Knowledge Management component of the UNPRPD. The resulting Global ToC was produced through an interactive, generative session whereby UNCT representatives described their processes and collaboratively iterated into a final, unanimous output. In this way, it developed from practice to theory, and can be reflected against the UNPRPD ToC working from theory to practice. It further contributes evidence derived from stakeholders across 10 Round 2 country projects to fill gaps in available knowledge.

This publication extracts findings from literature cited in the introduction and concepts explored in the conclusion of this study, arguing that social science research and practice can strengthen its impact on policy using a Theory of Change approach through desk analysis, workshop documentation and triangulation against previous findings across studies from this



PhD. The publication is expected to be submitted for review by the end of 2023 and published in the Oxford University Press edited volume, *Human Rights and Wrongs in Psychology and Psychiatry*.

### 3.6.2 Discussion: Connecting the publications

The first publication (Appendix A) outlined a theoretical hypothesis by synthesising existing theory in social dominance and change and applying it to a disability inclusive development context as seen in the UNPRPD. The analytical process identified key concepts that drove inquiry into the UNPRPD programme, and how large forces interact with it in practice, such as the UN SDGs and CRPD. The theory developed in *Macropsychology* (Wescott, et al., 2021) raised questions of dominance, decision-making, and overarching force fields elicited from Bourdieu's work. After the desk analysis in the *Global Development* (2021b; Appendix B) paper generated findings that align with concepts of various forms of capital and power in project selection, the next task was to collect primary data in country case examples to link theory to practice through an applied analysis.

The first case study returned unexpected results (Appendices C & D). From the first interview to the last, appreciative inquiry was met with responses expressing concern and frustration over the project's progress toward change. Bourdieu's suite of theoretical concepts enabled the expansion of the initial *Macropsychology* framework, connecting the structural to the intrapersonal known as *hysteresis*, and its return relationship to structural affiliation. It was clear by participant responses that there were forces exerting influence and constraints on the project, however, it also provided parameters by which some evidence did not fit into the framework and warranted separate inquiry. In the case of Uruguay, participants expressed puzzlement over the inability to find persons with disabilities to engage in the project. The consensus was so strong

across stakeholders that it was appropriate to reach for demographic data. Once statistical and Geographic Information Systems analyses were applied to the most recent Census data (2017), participant responses were better understood in conjunction with the theoretical framework. The research was split into two publications due to the broad scope of results and application of theory.

The final case study in Serbia (Appendix E) applied the same methods for internal validity and returned results in line with the initial design of appreciative inquiry, identifying the most significant changes from the perspective of multiple stakeholders. Bourdieu's theories were applied thematically, seen in capacity building (forms of capital), stakeholder engagement (social capital), subject matter expertise (cultural capital) and other key concepts. The primary goal of the project was to amend the Serbian Family Law, allowing the deprivation of legal capacity on the basis of disability. While the project activities and design were often different than that of the country project in Uruguay, the theoretical foundation provided a systematic way of analysing the data across both studies.

Research cited in the Introduction of this PhD advocates for the use of a ToC to shepherd activities through to impact, and the need to report and iterate against the ToC. The last publication (Wescott, et al., 2024; Appendix F) will explore the process of generating a collaborative ToC based on the practical experiences of UNCT representatives in their projects and reflect against the UNPRPD programmatic ToC and literature surrounding such theories in general. Given that the literature calls for ongoing revisions, the chapter will review the workshop data against the previous publications in this study, which collected input from government and civil society partners in addition to the UNCTs to identify possible gaps in stakeholder perspective. The findings will then be considered from a theoretical perspective as

seen in *Macropsychology* (2021a) and findings from *Global Development* (2021b). In doing so, the study will synthesise multiple data sources and key concepts informing the UNPRPD programme in a novel exploration of the ToC in theory and practice.

The final publication listed (Appendix G) was not formally part of this PhD by publication series, however, the paper argues provision of services such as assistive technology are critical in realising the CRPD. Technologies designed to adjust existing barriers are levers to realise various rights in the CRPD, including but not limited to Article 10: Accessibility, Article 24: Education and Article 27: CRPD Work and Employment. Framing assistive technology as a rights issue can inform local planning and leverage structural change, thematically in line with the research question from this PhD.

## 4. Conclusion

The introduction chapter outlined gaps in both the availability and approaches taken in existing knowledge, as well as theoretical gaps in the current literature (See Introduction: Theoretical Background). The first publication in macropsychology (Wescott, et al., 2021; Appendix A) was critical in designing the research question: *Is the UNPRPD programme triggering structural change, and if so, how?* Kuper et al. (2020) recommend increasing and improving the quantitative and qualitative evaluations of disability inclusion initiatives to better understand and guide implementation, and aligned with Asada et al., to not only have a ToC, but to report against it as a programmatic measure (2019). Further, *participation* of persons with disabilities and other key concepts were deemed critical, though largely undefined. This study contributes to the call for additional evidence by examining the UNPRPD programme at multiple levels. The findings provided a deeper understanding of partnerships between stakeholders, in particular, the role of persons with disabilities and their representative organisations as enshrined in the CRPD (UN, 2006) and UNPRPD ToC (2016). For example, using the same methods across both case studies, results showed varying degrees of participation, even when following the same programmatic framework. In Uruguay, the participating umbrella organisation lacked membership of persons with disabilities as well as capacity to engage as an equal partner, whereas in Serbia, relationships between UNCT representatives and civil society predated the project and informed the inception and activities that followed. These examples provide scientific evidence to the term *participation*, how the ToC is realised in different projects, and how projects might operationalise key concepts to strengthen implementation in future rounds.

As mentioned above and in the introduction, ToCs are a burgeoning tool in disability inclusive development, however, there remains limited evidence around the theory in practice. In

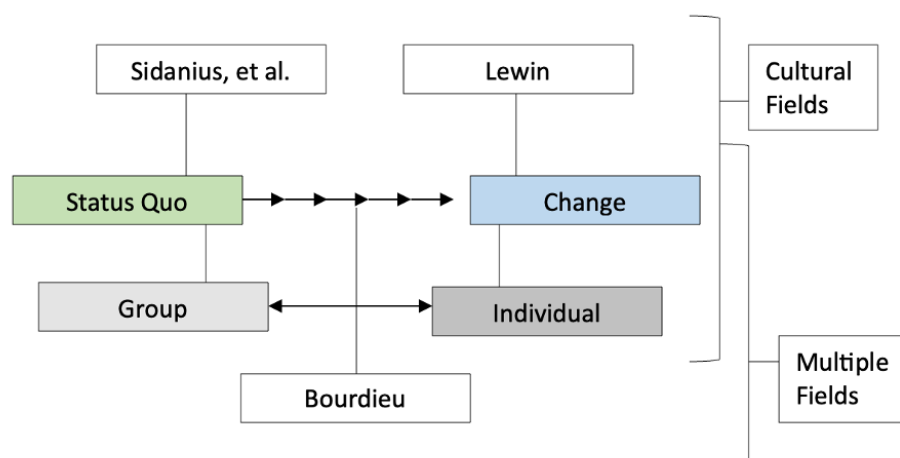
Asada et al.'s (2019) study of underrepresented groups in a medical setting, researchers evaluated an initial programmatic ToC and modified it based on key findings. Critical areas were identified in the early engagement phase of their ToC, noting readiness for change, capacity building and alliance strengthening, which were also seen in the case study findings of the UNPRPD programme (See Wescott, et al., 2021c; Wescott, et al., 2023; Wescott, et al., 2024). For example, the UNPRPD programme in Uruguay initiated the project based on recommendations and concluding observations from Committee to the CRPD reports and struggled to engage representative civil society and transition out of inception activities (Wescott, et al., 2021c; Wescott, et al., 2024). In contrast, UNCT representatives in Serbia had a longstanding relationship with civil society and drive the project themes based on existing capacity (Wescott, et al., 2023). As such, this study contributes supporting evidence applied in a disability inclusive development context, suggesting a ToC may require collaborative iteration to fully develop critical components and subsequent guidance for implementation, making a ToC a dynamic tool based on programmatic evaluations.

The choice of the Most Significant Change Technique and appreciative inquiry was designed to facilitate generative results from a range of stakeholders as global frameworks, documented knowledge gaps and the UNPRPD ToC call for, in a scientific and systematic way. The approach took into consideration forces of social dominance and removing structural constraints to participation across the multiple hierarchies embedded into each project (See Wescott, et al., 2021a). For example, representatives of a UNCT are part of a larger ecosystem of the United Nations, though some faced challenges with the programme design (e.g., lack of project coordinator in both case studies). Further, not all stakeholders were created equally in the partnership, such as OPDs having a 'seat at the table' for the first time with government and

UNCTs, which often had an established working relationship. Tension in a stakeholder's position was important to be mindful of during the design phase of the research question and methods. Using a standard tool sensitive to such power differentials contributed to a robust and holistic exploration of country projects as a phenomenon, inclusive of voices most often left out. This was in itself a significant contribution to the gap in knowledge, particularly as participation of persons with disabilities and their representative organisations are enshrined in the CRPD and increasing in disability inclusive development initiatives.

The literature also identified a need for more effective measures in disability inclusive development to capture the complexity and diversity of development initiatives. Not only did this study provide a variety of research products, including both quantitative and qualitative methods, it also developed a theoretical framework proposing a new approach to measuring change. Existing theories such as SDT, Lewin's intentional change, and Bourdieu's field analyses provided a baseline and identified existing theoretical gaps (see Figure 2) to inject concepts from disability models and barriers to frame a new research paradigm, published in Wescott et al., 2021a and applied in Wescott et al., 2021c, Wescott et al., 2023 and Wescott et al., 2024.

**Figure 2:** Conceptual Framework across social theorists and key concepts



**Table 6:** Social theorists and components of social dominance and change

<b>Theorist</b>	<b>Forces</b>	<b>Social impact</b>	<b>Dominance</b>
Sidanius et al.	Cultural myths	Hierarchies	Groups
Lewin	Social construction	Deconstruct/reconstruct	Individuals
Bourdieu	Capital	Rules of the game	Durable capital

All of the components in Table 6 appeared in the data, however no single theory provides a complete framework to understand the UNPRPD programme and structural change towards disability inclusion. For example, Sidanius et al., asserts dominant myths maintain inequality (1992). Bourdieu agrees, describing historical possession of capital creates a legitimising and durable position between structures, upholding historical dominance (also known as hierarchies). The case studies in Serbia and Uruguay support their claims; however, Sidanius et al.'s theory does not provide a distinction between culturally embedded myths in a social group and the introduction of legal frameworks developed outside those local hierarchies, but nevertheless adopted into them. The scope of application is framed by cultural, group-based myths, which are diverse and multiple across contexts. In the case of the UNPRPD, the Convention introduced a new myth which opposed the cultural narrative, with additional force as an international treaty. Bourdieu's theory recognises multiple and overlapping hierarchies and fields, containing complex compositions of power and varying levels of dominance. Such a landscape was evidenced in the UNPRPD programme and is useful in designing future research to capture evidence not found in traditional metrics.

Unlike the previous two theorists, Lewin presented stages to implement intentional change, which involved an analysis of project conditions, 'unfreezing' and 'refreezing' to the desired state (Lewin, 1943). Projects are deployed by individuals, as opposed to Sidanius et al.'s

focus on groups and Bourdieu's feedback loop between them. Lewin recognised the influence of environment on the individual in what he termed *life space*, however, he drew a clear distinction between the two. One can see his influence on projects in international development, suggesting actors can enter a context and provide aid and development to 'beneficiaries' as separate entities. There has been a recognition of Western influence in international development as we see a broader shift towards participation on an equal basis and local ownership, rather than project implementers distinct from their context. Bourdieu also recognised the relationship between the individual and their respective environment via *habitus*, highlighting the embodiment of structural associations. The studies in this PhD show a strong relationship between individuals and their respective structures. For example, in Wescott, et al., 2021b, an analysis of Round 1-3 UNPRPD country projects and their thematic priorities selected for funding strongly aligned with existing UN thematic agencies, such as education, employment and health. While individuals designed and proposed projects at the country level, the majority fell into existing organizational structures. Lewin's theories remain useful alongside Bourdieu but measure different things. Project deliverables seen in the UNRPDP annual reporting follow similar steps outlined by Lewin and are helpful to follow milestones and activities. As evidenced in the Knowledge Gap section of this study's Introduction chapter, little information is available, even in traditional reporting.

The individual was referenced as significant in the UNPRPD country case studies, both in the ways Lewin intended and in ways that challenge his model. For example, activities relied on key actors with subject matter expertise, but in some cases, were not readily available. In Serbia, the mentorship programme and key UNCT representatives drove a participatory design and selected themes with readiness for change (Wescott, et al., 2023), supporting Lewin's approach.



However, in both Uruguay and Serbia, there were project plans and actors working to identify, unfreeze and refreeze barriers, yet external forces continued to exert pressure, including organisational capacity limitations, durable myths, and programme parameters (Wescott, et al., 2024; Wescott, et al., 2023; Wescott, et al. 2021c). As such, this study also found limitations of scope in Lewin's model. Like Sidanius et al., who were useful in understanding a broad cultural myth or field, such as the myths government may have about disability and how those myths reinforce hierarchical positions. The intersection of various fields, such as the nested hierarchies within the United Nations over each country project uncover additional forces propelling and challenging such myths. Lewin was useful for project-level thinking and designing change as is seen in the UNPRPD ToC. However, stakeholders carried histories into the projects, making a linear procedure to initiate change troubled in practice.

Bourdieu's theories were highly conscious of practice (Bourdieu, 1977; Grenfell & Lebaron, 2014; Maton, 2003). He wrote extensively about the relationship between state and agent, and the reinforcing feedback loop between them (Bourdieu, 1977; Bourdieu, 1987; Bourdieu, 1990). The idea that capital is durable but relational allows for a dynamic field with players shifting and holding multiple positions. This PhD upholds this stance, finding for instance that stakeholders may have dominance in decision-making but struggle to implement it without a fully realised tripartite partnership. Changes may occur for an individual from a dominant structure like government or the UNCT, while finding their range of influence is limited by the larger organisational ecosystem and struggle to mainstream learnings from within the UNPRPD. In this way, structural change itself has many layers from which to evaluate. One can look deeply within the project, UNPRPD programme, UN organization at large and beyond with the theoretical application used in this study.

Evaluating complex programmes such as the UNPRPD with multiple stakeholders from across social hierarchies and social positions cannot be fully understood without recognition of the multiple forces, both historical and introduced, surrounding country projects, the overall programme and surrounding social fields. As such, this study captures both scientific evidence and applied analysis for how social theory can be leveraged in novel ways to understand structural change in disability inclusive development, contributing to the need for more robust, contextualised data in many forms.

The research question asked if the UNPRPD programme is triggering structural change, and if so, how. There was evidence of rights being newly upheld because of the UNPRPD. In Serbia, individuals with IDD deprived of their legal capacity were involved in the project, which aligns with the CRPD Article 4.3 mandating participation of persons with disabilities and their representative organisations in decisions, particularly those affecting them (2006). The rights of women and girls with disabilities were practiced through peer mentoring by providing a place for women who experience multiple intersecting forms of discrimination to participate in discussions and processing social barriers. These activities created an opportunity to inch closer to realising rights on an equal basis to others, if only in the small groups that participated.

Both case studies reported shifts in cultural and social capital through awareness, new stakeholder relationships and budding interest in other disability projects as a result of the UNPRPD. The changes did not fundamentally alter the landscape of power in two years, but they almost unanimously brought disability rights ‘to the table.’ This research and the theory used to frame it was valuable for capturing the process of burgeoning change. It recognizes the cyclical relationship between embodying knowledge about disability rights and how that continuously works to construct new social norms, though perhaps more in some countries than others.

Further, the changes targeted by the UNPRPD are upstream- macro interventions or changes that persons with disabilities may never know about. While Article 4.3 CRPD argues those affected should always be involved (and were in Serbia during the drafting stage of the Family Law amendment), the UNCT played a significant role with their legal expertise of national law, legal capacity and the CRPD at large. There was presence of persons with disabilities and inputs were collected, as well as awareness building and about the Family Law and legal capacity while it was undergoing reconstruction. This is not the same as direct participation, which the project and programme espouse, but it does include powerful actors that have embodied the disability rights paradigm into structural change. These things are not mutually exclusive. However, until key decision makers are comprised of persons with disabilities, key connectors such as in Serbia's UNCT act as a bridge to participation.

While neither project resulted in systematic reform or amendment to national law by the close of their term, the UNPRPD programme seems to have triggered early and deeply structural change within the partnerships, which were chosen for being critical to larger scale change. At the same time, changes were largely experienced by people involved with projects and not at a national, or even entity level. For example, there was no evidence that the individual stakeholders representing the government transferred their acquired knowledge across the entire ministry. In both cases, the individuals within each partnership acquired deep knowledge and momentum that became even more valuable to participants' hope for 'real' change as the funding cycle ended. This was evident in the risk of changing government in Uruguay and participants in Serbia that bridged both the UN and civil society. The reality of implementing the UNPRPD ToC in projects such as in Uruguay and Serbia can be more complicated than it is a turnkey model. Both projects ended after one funding cycle, and little is known about the partnerships

and priorities after a project is closed, or if the individuals embodying the changes are keeping the story alive.

#### 4.1 Recommendations

The research publications from this PhD serve as an introduction for deeper inquiry, as little evidence was available on such a significant global programme. More longitudinal research of diverse rounds of projects beyond the first inception round will capture change over time. Additional research should explore both the UNPRPD programme and the changes it triggers with country and regional projects. For example, does the UNPRPD reflect on and address programmatic barriers such as the need for a project coordinator and the use of national and umbrella organisations as seen in Uruguay, and who has the authority to change course (Wescott et al., 2021c)? Another key programmatic issue drawn from the data is the selection process for project priorities and would benefit from deeper examination.

In addition to longitudinal research for projects with multiple cycles, there is an opportunity to explore countries with a gap in projects or to revisit countries after a project closes. Future research could engage the same participants in Serbia and Uruguay to see what the impact, if any, was the result of their project ending before the set activities were implemented. For projects that get another round of funding, are they continuations of the first? How are the impacts of projects measured if they cease to exist after two years? Is the programme addressing the needs of persons with disabilities and local barriers if most projects fall within the same priorities? Is the UN the right organization to host these projects with limited technical expertise across the CRPD and local relationships? Alternatively, a study could review the UNPRPD projects at large and look for instances of normative change. How many national laws have been amended from a UNPRPD project, and has it ever happened in a single round of funding? How

much time does it take to implement such changes, and should a two-year project cycle be reconsidered? What were the most significant factors behind the adoption of project priorities in those that did? Given that governments are ultimately responsible to enact amendments such as those proposed in Serbia, if these pursuits are dropped when a project ends, can it truly be called a ‘partnership’? Crucially, what happens to the capital composition of stakeholders when a project leaves? Anecdotal conversations with participants from an earlier study in Armenia (Wescott, 2017) and this study in Serbia suggested there may be a dissolution of these critical organisations after funding and partnerships cease. These concerns should be prioritised and researched to evolve the UNPRPD ToC, provide a deeper understanding of what projects constitute as ‘real’ change, and ensure the programme does not drain more capacity than it builds.

Both studies reported a stronger partnership between only two of the three primary stakeholder groups. In Uruguay, the UNCT was operationally engaged with government ministries, whereas in Serbia, the UNCT and civil society were more connected. According to Bourdieusian theory, it would be unusual for the UNCT to have such a strong relationship with an opposing entity across social space. They shared capital exchanges through cultural and social networks, but the economic, status and institutionalised differences between them position the UN closer to government in terms of power concentrations, as explained in the Macropsychology chapter (2021). Noting the relationship between the UNCT in Serbia and their civil society organizations focusing on legal capacity of persons with disabilities, additional research is recommended to explore the cultural and social capital exchanges between close, opposing entities, what maintains their distance despite such capital, and how individuals flow from one area of social space to a drastically different one as was seen with some of the UNCT members

having previously worked in Serbia's civil society. Additional research can help identify what factors enable such mobility across social space.

The UNPRPD is both building capacity toward meaningful engagement and leveraging it to launch a project. The majority of UNCT representatives engaged in the UNPRPD had never worked in disability rights or handled the CPRD prior to their project. Some projects begin with priorities before having the capacity required to deliver results, conceived primarily on CRPD Committee reports and UN Agency availability. Based on the findings of this PhD, engagement alone can use the available resources when creating new partnerships and leave little time or capacity for planned activities. There may be additional ways to support projects under the UNPRPD programme, for example, projects for coalition building and others for countries with established partnerships to target normative changes, which may require extended support. Both continue to foster and expand the partnership model of the UNPRPD but may create more space for countries at different levels of capacity.

#### 4.2 Implications of the study

This research recognises the complexity of structural exclusion and the value of studying how root causes inform the process, along with subsequent social impacts. Examining how change initiatives at the transnational level are developed and implemented by structures is essential, considering this is the first time many states are confronting disability rights with a tripartite, rights-based approach. These initiatives have their own logics that contextual operations, then engage local government and civil society to challenge normalised barriers that exclude persons with disabilities. Documenting the process, questioning it and capturing the changes required to achieve the full and meaningful participation of persons with disabilities will assist in the global transformation of disability rights into everyday practice.

The edited volumes and journals selected for publication were interdisciplinary, however the data was collected from a psychological approach having inquired individual participants about the UNPRPD project from their perspective. The responses were analysed to understand the process of change, something theorists like Lewin and more contemporary ToCs seek to articulate. Given that Bourdieu theorises individual perspectives are constructed through structural forces, the lens from which participants spoke from engaged values, priorities, and conclusions as a uniquely macro and micro psychological approach. Future researchers can bring to light the relational forces within and between individuals and their surrounding structures that are present in all interactions to support disability inclusive development in large scale programmes.

Based on the rich contextual data provided by participants in all stakeholder groups and early stages of the projects, this PhD provides both theoretical and practical value to researchers and disability rights practitioners.

#### 4.3 Reflexivity

I have spent over 12 years of my professional career as a sign language interpreter working in the intersections between the worlds of disability and non-disability. The nature of some barriers to social inclusion means that persons with disabilities experience them alone (e.g., buildings without a ramp present a barrier between the individual in a wheelchair and the stairs). In contrast, I transact these moments in Deaf persons' lives in my occupation. For example, each time a physician states an assumption about a Deaf person, I take in the comment, process it and express it directly to the Deaf person as authentically as if I were the one who made the assumption. Such moments accumulate over time, providing visibility into what it means to be socially excluded on the basis of disability. This concept grows into vital knowledge that

becomes my strength in researching power relationships and disability exclusion. Power differentials are highly nuanced and disguised as normal. My training is to pay heed.

From a Bourdieusian perspective, sign language interpreters bridge the space between the key concepts of doxa and habitus. In interpreting appointments, I meet people from opposite ends of social space, equipped with their embodied ideas (habitus). Interpreters work to make sense of individual exchanges between people from two different worlds in a range of settings (doxa) that have been designed in a way that excludes the person with a disability (reflecting the reason I have been brought in to interpret). With that said, I too hold a habitus, which is always evolving with new embodiment of my own doxa and those I position myself between as an interpreter.

In interviews conducted for this thesis I would introduce myself by positioning my proximity to the subject. I would tell participants I was a researcher, a sign language interpreter, and someone who has been involved in disability for many years. In a conversation with a government representative in Uruguay, she shared that she studied sociology. In return, I shared my interest in Bourdieusian theory, then she continued our conversation by framing her thoughts through his lens. We all made an effort to relate, and I was much more present in the room than in my role as an interpreter, because interpreters try to bridge the divide between others, but not oneself and others.

No interpreter is wholly authentic to the rooms we work in, and it changes upon entering. The same was true for my interpreters in the country. I acquired a preference for one interpreter in Uruguay because my conversations felt more direct with the participants than with another, and I continued with my preferred interpreter for all interviews that followed a contrasting example. I aimed to preserve the internal validity as interpretation contains subjective word



choices that come from the mental model of the interpreter. With this learning, I piloted an interpreter in Serbia and used the same person for all interviews in Serbian language. Interpreters are often the only ones in the room that know what everyone is saying, and it was a change for me to need another voice to convey my meaning. I was aware that my preference for interpreters meant I wanted someone that conveys who I am, and thus my habits, in the conversations.

#### 4.3.1 Bracketing bias

While I was more exposed as myself in the interviews, the data analysis used my strengths as an interpreter in a delicate balance between maintaining the authentic voice of the individual participants and interpreting meaning from various angles. Such perspectives might represent an individual's point of view informed by their position, power dynamics and role in the project. Understanding these factors is essential to reading the intent behind any individual utterance in an interview. Professional standards upheld by the American Sign Language (ASL) interpreting licensure body, the Registry of Interpreters for the Deaf (2005), such as ethical boundaries to maintain the integrity of individual thoughts and expressions without interference or alteration during an interpretation, were also applied to the data analysis. For case study analyses in this study, interpretation following IPA protocol took place at two points: the thematic coding of participant reflections and the Bourdieusian analysis of the data. Great care was taken to maintain authentic interpretations of the participant responses at both stages of analysis.

The same set of questions (MSCT) was used for all participants in both case studies. While many participants found some questions difficult to answer directly, the research consistently applied the semi-structured interview questionnaire to reduce bias between participants or country cases. Many participants did not respond to the MSCT by answering the

questions with stories (see Uruguay publications). However, flexibility was a key element in the study process, reflecting Smith et al.'s (2009) emphasis on flexibility during an interview to allow for deeper engagement in the statement, "Participants should have been granted an opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length" (p. 56). Using the MSCT in a semi-structured manner provided a consistent prompt that allowed participants to reflect without limiting possible responses, leaving room to explore in depth the varying participant experiences.

The use of theory helped to reduce researcher bias during the second stage of analysis. Interpretation translated information from one form to another without altering the message. The fidelity of the message was the priority through all stages of data analysis, from understanding the original message according to varying perspectives to theoretical conceptualisation of the UNPRPD phenomenon in two countries. Bourdieu's theoretical concepts to support and explore themes that emerge from the data were applied in lieu of an entirely personal analysis, reducing the impact of researcher bias.

Notably, these case study analyses represent an interpretation from the PI, mitigated through academic guidance in ethics, professional conduct for interpretation and theory to support the findings. Another researcher, working from different theoretical perspectives, might frame the data differently. Although the lens of another researcher might vary, the results would similarly reflect the published case studies as the aim of this study has been to present the data authentically with transparent interpretations and application of theory.

After data-gathering and early review of the evidence, informal meetings were held at the 2019 KnowUNPRPD conference in London, England with UNPRPD liaisons to follow up and discuss some of the findings. Additionally, a presentation highlighted preliminary findings from

the study to the UNPRPD cohort and UNPRPD Technical Secretariats. In both the meetings and the formal presentation, the Uruguayan and Serbian liaisons affirmed the findings, triangulating the superordinate themes identified in the early stages of the analysis.

#### 4.4 Limitations

Although phenomenological research offers many positive aspects, one limitation of the study is that the data collection represents a snapshot taken during a 24-month project. The interview tool was designed to engage participants in reflection at any point in the project cycle, and interviews took place before the first round of programming was complete. The evidence is presented while recognising that the full extent of change will continue to unfold.

All research designs have limitations. In the case of this research, one limitation was the purposive sampling approach. Limited time in each country created a convenience constraint regarding who was available to be interviewed. This tended not to be an issue as the sample size far exceeded the minimum number needed for a comprehensive study; however, some stakeholders provided more individual responses than others. For example, in Uruguay, nine government focal points were interviewed from seven total participating institutions, while only two of the civil society representatives within the partnering umbrella organisation participated in interviews. Securing an even distribution of voices from each stakeholder perspective reflecting the project designs offers an inherent challenge. The UNPRPD project in Uruguay engaged seven government institutions and one civil society coalition organisation without a central operations team. In this way, the numbers of participants in each participant group were not equal, though the responses were proportionate to the distribution of partnerships within the project.

Finally, the interview participants did not respond to the MSCT tool as the researcher anticipated. MSCT is an appreciative inquiry, reflecting on the positive aspects of participant's experience with the UNPRPD project. The rationale for exploring positive changes is to engage participants regardless of position in complex, hierarchical circumstances (Quilliam & Wilson, 2011). The research recognises that the purposive sampling originated from recommendations by the UNPRPD country team, making appreciative inquiry a conscious decision to reduce concern over power dynamics in how individuals responded. That being said, many participants (including UN representatives) hesitated to share positive feedback about the project, opting to share concerns. Nevertheless, meaningful data was generated from the participant responses, both critical and positive. The learning derived from each case study shows the complexity of structural interventions and a partnership approach between entities of varying capacity.

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Wescott, H., MacLachlan, M., & Mannan, H. (2021). The macropsychology of disability rights and structural change: Using Bourdieusian analysis to understand stakeholder

power relations. In M. MacLachlan, & J. McVeigh (Eds.), *Macropsychology: A population science for Sustainable Development Goals* (pp. 175-187). Springer.

7. **Appendix B: Wescott et al., 2021**

Wescott, H. N., MacLachlan, M. and Mannan, H. (2021). Disability Inclusion and Global Development: A Preliminary Analysis of the United Nations Partnership on the Rights of Persons with Disabilities programme within the context of the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals. *Disability, CBR & Inclusive Development*, 31(4), 90–115. <https://doi.org/http://doi.org/10.47985/dcidj.397>

8. **Appendix C: Wescott & MacLachlan, 2021**

Wescott, H., & MacLachlan, M. (2021). Implementing ‘real’ change: A Bourdieusian take on stakeholder reflections from the United Nations Partnership on the Rights of Persons with Disabilities project in Uruguay. *SN Social Sciences*, 1(12), 282. <https://doi.org/10.1007/s43545-021-00280-w>

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10. **Appendix E: Wescott et al., 2023**

Wescott, H., Ferri, D., & MacLachlan, M. (2023). Participation, legal capacity and gender: Reflections from the United Nations Partnership on the Rights of Persons with Disabilities project in Serbia Disabilities. *Disabilities*. 3(1),129-146.

### 11. Appendix F: Wescott et al., In press

Wescott, H., MacLachlan, M., & Mannan, H. (In press). The use of a Theory of Change to promote knowledge management and global implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In M. MacLachlan, I. Ebuenyi & B. Kelly (Eds.), *Human Rights and Wrongs in Psychology and Psychiatry*. Oxford University Press.

### 12. Appendix G: Smith et al., 2022

Additional publication (separate from thesis): Smith, E., Huff, S., Wescott, H., Daniel, R., Ebuenyi, I. D., O'Donnell, J., Maalin, M., Zhang, W., Khasnabis, C., & MacLachlan, M. (2022). Assistive technologies are central to the realization of the Convention on the Rights of Persons with Disabilities. *Disability and Rehabilitation: Assistive Technology*, DOI: [10.1080/17483107.2022.2099987](https://doi.org/10.1080/17483107.2022.2099987)

### 13. Appendix H: Informed Consent form

Malcolm MacLachlan  
Joanne McVeigh *Editors*

# Macropsychology

A Population Science for Sustainable  
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# Macropsychology

Malcolm MacLachlan • Joanne McVeigh  
Editors

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A Population Science for Sustainable

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# Development Goals



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*To Eilish, Lara, Tess and Anna-Helena  
– Mac*

*For my wonderful family, friends,  
and colleagues. – Joanne*



# Preface

This is a research volume that brings together social, organisational, cultural, and health psychology research concerned with a macropsychology perspective. Macropsychology is concerned with ‘understanding up’, or how we can influence the settings and conditions of the society in which we live. Psychology has traditionally been more interested in ‘understanding down’, that is, with the behaviour of individuals and groups, in inter-psyche and intra-psyche and in neurological and biological processes. This volume argues for the development of a macro perspective within psychology. While behavioural change at the macro level is a key feature of other disciplines such as sociology, economics and law, it is a neglected perspective within psychology. If psychology is to be relevant at the global level – addressing grand challenges and global goals, using big data, and intervening at the population level – then it needs to better articulate its contribution at the macro level. The macro perspective within psychology will position it also within the realm of population sciences, allowing us to contribute to designing society according to what is *psychologically right for humans*, spurring the application of psychosocialism across multiple domains.

This volume draws on the inspiring work of those who have been developing a macro perspective under various guises within psychology and related fields. Some of the most prominent proponents of this perspective are contributors to this volume. We make no claim that this volume is comprehensive or exhaustive. Rather, the chapters in this volume demonstrate the broad range of areas to which a macropsychology perspective may be valuably applied, including mental health, personality, public persuasion, culture, disability, agent-based modelling, decent work, humanitarian work psychology, urbanisation, food systems, and deliberative democracy. These areas of inquiry are of great significance – and some integral – to the realisation of the Sustainable Development Goals (SDGs). Indeed, there is increasing interest within psychology to contribute to achieving the SDGs. It is becoming a vibrant area, to which a macropsychological perspective can contribute much.

We wish to extend our gratitude to the contributors of this volume, and to Springer for their support in bringing this volume to fruition. The book – like

macropsychology itself – is ambitious. It aims to recognise and give impetus to the development of a neglected perspective within psychology and to stimulate a paradigm shift towards psychology incorporating *social structures, systems, policies, and institutions* into its purview. Doing so would enable psychology to more effectively implement its findings, embrace big data more instrumentally, and facilitate greater involvement with concerns about social justice, inequality, and human rights .

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# The Macropsychology of Disability Rights and Structural Change: Using Bourdieusian Analysis to Understand Stakeholder Power Relations



Holly Wescott, Malcolm MacLachlan, and Hasheem Mannan

The *World Report on Disability* (World Health Organization & World Bank, 2011) estimates that about 15% of the world's population – over one billion people – live with some form of disability. In comparison to people without a disability, those with a disability have higher rates of poverty; lower rates of economic, political and cultural participation; lower levels of educational achievements; and poorer health outcomes, along with increased dependency and less legal protection (WHO & World Bank, 2011). The United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted by the United Nations General Assembly in 2006 (UN General Assembly, 2006), acknowledges both the historic and the current and pervasive discrimination, exclusion and marginalization of people with disabilities. The CRPD specifies the duty of states parties (nations) to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms, by all persons with disabilities.

Psychology has contributed much to understanding and addressing some of the challenges experienced by people with disabilities (Goodley & Lawthom, 2006). Psychology's contribution in this regard may however be broadly characterized as adopting more of an individual/clinical/medical model perspective, rather than a social/structural/human rights model perspective (MacLachlan, 2012; MacLachlan & Mannan, 2014). We have argued that 'barriers to implementation of the Convention on the Rights of Persons with Disabilities are embedded within longstanding social

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structures and attitudes that do not give way easily. Often such discriminatory practices—even when not necessarily intentional—are nonetheless “protected” because of the advantages that accrue to others “the advantage of keeping things as they are, of maintaining the status quo” (MacLachlan & Mannan, 2016, p. 102). The attitudes held by individuals and the social structures that channel our experience of disability co-construct one another (MacLachlan, Mannan, & Wescott, *under review*). Social institutions, such as schools or health services, policies or laws, or norms or conventions, mediate the patterns of our social relationships. As macropsychology has been defined as ‘the application of psychology to factors that influence the settings and conditions of our lives’ (MacLachlan, 2014, p. 851; MacLachlan, McVeigh, Huss, & Mannan, 2019), then the impact of social structures on human behaviour should be a concern for psychological research and practice on disability. However, psychology rarely addresses the effects of power relationships mediated through social structures (MacLachlan et al., 2019) and in order to do so may benefit from interweaving other complementary approaches to understanding and changing human behaviour. This chapter explores how some of the key concepts of Bourdieusian analysis may contribute to a better way of intervening to address the settings and conditions of people’s lives. It does this by considering power relationships within a United Nations programme that seeks to promote the rights of people with disability through addressing structural barriers.

The UN Partnership to Promote the Rights of Persons with Disabilities (UNPRPD) brings together UN organizations, governments and civil society – including Organizations of Persons with Disabilities (OPDs) – and other partners to promote the rights of persons with disabilities through implementation of the CRPD. The UNPRPD is funded through a Multi-Partner Trust Fund (MPTF) of just over \$28 m provided by a range of donor countries (MPTF, 2018). The partnership has worked in 38 countries and with 2 regional networks (the Pacific Disability Forum and the African Disability Forum) since it was established in 2014. To give a sense of the sorts of foci across these countries and projects, Table 1 indicates some of the main structural issues addressed by the UNPRPD. The KnowUNPRPD is the knowledge management component of the UNPRPD, incorporating provision of intensive week-long training workshops, personal coaching and a help desk providing analysis and feedback for draft applications to the fund. The KnowUNPRPD also conducts programmatic research, and it is from this component of the programme, funded by Irish Aid, that the current chapter arises.

The overall approach within each of the countries in the UNPRPD has been to develop a Theory of Change (ToC), to guide stakeholder interaction towards agreed targets (see UNDP, 2016a,b; UNPRPD, 2018). The Theory of Change approach is based on the social and organizational psychology of Kurt Lewin, particularly his conceptualization of Force Field Analysis (Lewin, 1943), which has now become a guiding approach across many domains (Breuer et al., 2016; Breuer, Lee, De Silva, & Lund, 2015). As De Silva et al. (2014) argue, ‘ToC is not a sociological or psychological theory such as Complexity Theory or the Theory of Planned

Behaviour, but a pragmatic framework which describes how the intervention affects change. The ToC can be strengthened by inserting sociological or psychological theories at key points to explain why particular links happen' (p. 2). While the ToC approach

**Table 1** Factors in the UNPRPD related to facilitating structural change

Enabling factor	Programme thematic priority
Enabling legislation and policy frameworks	Promote the ratification of the CRPD whenever relevant and the development (or reform) of legislation and policies (disability-specific and not) as well as strategies and action plans
Empowering and challenging cultural norms	Reverse stigma, prejudices and negative stereotypes while promoting supportive and empowering attitudes
Capable and inclusive institutions	Strengthening the national disability architecture by developing the capacity of national disability authorities and Organizations of Persons with Disabilities (OPDs)* through enhancing dialogue
Access to services (mainstream and targeted)	Enhancing access to mainstream as well as targeted services by improving their design and delivery modalities and by promoting measures that will increase availability and affordability
Access to justice	Increasing access to justice for persons with disabilities and the capacity of the justice sector to appropriately respond to the specific circumstances of persons with disabilities
Application of accessibility standards	Promoting the application of accessibility standards to products, environments and processes, including non-disability-specific interventions and universal design initiatives
Adequate access to rehabilitation, habilitation and assistive technology	Improving access to rehabilitation and habilitation – including assistive technology – by strengthening the availability and affordability of services and improving the design of assistive technologies
Adequate data and evidence	Improve disability-specific data and support research on different aspects of disability

Adapted from UNDP, 2016b

\*The broadly accepted name for such organizations has changed since the original submission. This is the updated, widely accepted term.

has been used in many contexts, we do not believe it has been used at the national level to address social structural change, particularly from a psychologically informed perspective.

## Integrating Lewin and Bourdieu

Kurt Lewin integrated ecological perspectives into psychological theory (Hobman & Walker, 2015). His concept of planned change provides an extensive range of tools to understand and initiate change (Swanson & Creed, 2014), considering facilitators for and barriers to change in a social context. However, one essential element of social change, which psychology in general, Lewin, or more recent works

on theories of change have yet to deal with effectively, is the crucial importance of power relations, symbolism and particularly different forms of ‘capital’ that are held by, or attributed to, different stakeholders. One notable exception is the work of Pratto and colleagues (Pratto, Sidanius, & Levin, 2006; Pratto, Stewart, & Zeineddine, 2013) which addresses social dominance in relationships between different groups, particularly marginalized and mainstream groups. However social dominance has not been used to our knowledge in Theories of Change, in the sort of low- and middle-income contexts that the UNPRPD is being applied.

The French social theorist, Pierre Bourdieu, extended Marx’s ideas of the importance of economic capital in shaping ones’ position and opportunities in society to non-financial types of advantage and identity. While his work was largely focused on social class, it has also been applied to disability. In this chapter, we provide a Bourdieusian analysis of power relationships within the UNPRPD to illustrate how macropsychology may benefit from incorporating some of the concepts developed by Bourdieu and by allowing itself to enter into the reality of power relationships influencing attempts to produce social and behavioural change. Pierre Bourdieu’s work has been used to explain disability exclusion, both as a general concept (Byrne, 2018; Edwards & Imrie, 2003) and the complex interactions described in both the production and reconstruction of historical norms (Bourdieu, 1984, 1998; Bourdieu & Wacquant, 1992).

One of the core claims of Bourdieusian theory is that all society is relational and the space between structures is what defines their boundaries (Bourdieu, 1987; Calhoun, LiPuma, & Postone, 1993). Bourdieu describes the structural world as ‘a set of constant relationships which are often invisible’ (Bourdieu, 1987, p. 3). These relationships operate based on power, or *capital*, and possession (or lack) of power distinguishes, positions and maintains these structures (Bourdieu, 1984, 1987; Calhoun et al., 1993). Four types of capital manage structural relationships and, therefore, the exclusion of people with disabilities from social participation at a system level. Forms of capital according to Bourdieu (1986) include monetary resources (economic capital), knowledge (cultural capital), non-financial social networks (social capital) and status (symbolic capital). Bourdieu recognizes power is translated into resources (e.g. specialized knowledge operationalized in development programming or entry to a specialized occupation with high income), and resources of all kinds are finite (Bourdieu, 1986). Structures (for instance, professional associations) then have an interest in acquiring or maintaining the capital necessary to remain influential, resulting in the organizational tension that makes change difficult to initiate, particularly when structures in power could be called on to redistribute their resources in the interest of equity (Bourdieu, 1989, 1998; Topper, 2001). For instance, the profession of psychology may resist other professions using psychometric tests to assess intellectual disability, even if the lack of psychologists to do this assessment may mean that there is a lack of access to services needed by people with disabilities. Capital exchanges (in this case, say, sharing expertise in psychometric testing and giving other the authority to also use them) are the sort of behaviour that we want to capture to measure the change in relationships between structures, as well as the forces that complement and compete with such efforts.



Cultural capital is broken down into three subgroups, described as information that is directly acquired (embodied cultural capital), standardized into some formal qualification such as a postgraduate degree (institutionalized capital) and objects that can be used to display and share knowledge, such as assistive technology or documentary films (objectified capital) (Bourdieu, 1986).

These forms of capital are more powerful when they work together and can result in a lack of exercisable power if acting alone. For instance, specialized knowledge of the human rights disability paradigm has little movement without the cooperation of a social network to disseminate and may act only as ideology without the financial resources to address the real costs of development. Reaching a symbolic status where persons with disabilities receive accommodations necessary to reduce institutionalized barriers therefore requires a significant amount of each form of capital. This is why Bourdieu emphasizes structural integrity is a product of the *volume* (amount) and *composition* (type) of these forms of capital (Bourdieu, 1986). Both the amount and types of capital determine what makes a structure stand in *social space*, and mapping, as Bourdieu methodology recommends, serves as a tool to explore the process and progress of structural change.

## Theoretical Alignment

The epistemological standpoint of Bourdieusian theory is that knowledge is acquired relationally, and the lines of distinction between what is constructed from the past to ongoing social constructions are capital and one's proximity to that power (Bourdieu, 1987, 1989). In the case of disability, those with capital (power and influence) have constructed an exclusive social space and lasting paradigm of disability (for instance, the use of a medical model and exclusionary norms by physicians). While other paradigms have been legitimized (social model, human rights model, social inclusion agendas), the impact on society is much less potent as a result of prolonged exclusion or lack of relative capital to make these changes affect social practices. This relationship is both abstract in theory and literal in mapping social spaces by identifying the distance between structures. For example, people with disabilities may feel very 'far' in terms of their ability to access a preferred job based on the societal misperception linking disability with lack of capacity and therefore face discrimination in areas of employment. The felt distance represents the relationship in social space between the person with a disability (or collective of persons with disabilities experiencing similar discrimination) and marginalizing attitudes and behaviours contained in hiring or promoting practice held by entities that have the capital to choose based on normative expectations. Access to social entities that have historically been 'out of reach' is the aim for much of the UNPRPD programme.

Social structures with similar volume and composition of capital are located close within social space, resulting in clusters of structures that appear relatively homogeneous to each other (Bourdieu, 1984, 1987). Government ministries have a long history of working with systems such as education. As a result, these entities

have an open line for exchanging resources such as funds, compliance to national standards and mutually reinforcing approaches to bringing up future generations of any society. As resources pass back and forth between these structures, the common threads between them strengthen and appear ‘close’ in their structural relationship. This is opposite to a structure representing persons with disabilities, as exclusionary actions such as institutionalization removed children from schools, and away from civic awareness, leaving an entire population at a great distance from decision-making bodies and other powerful entities. Current evidence shows this phenomenon is occurring all over the world (WHO, 2016; WHO & World Bank, 2011), where disability is relationally marginalized from larger societal influence. When applied to theory and the UNPRPD programming, these positions and trajectories serve to not only depict exclusion at a structural level but can also reflect how they can transition to become inclusive over time.

## Unlocking Systems

One way of describing the border between inclusion and exclusion is through Bourdieu’s *fields of power*, which provides a concrete way to document the global issue of structural exclusion declared in recent disability priorities such as the Sustainable Development Goals (SDGs) and CRPD. When mapping social space, structures with a large volume and diverse composition of capital (resulting in overall influence) are placed in opposite directions, as if on an *X*- and *Y*-axis, to those without such capital. Stakeholder relationships in intervention projects confront complex and often competing priorities, including the forces that drive their different interests (Department for International Development, 2009; Esteves & Assuncao, 2014). Bourdieu asserts the forces driving structures derive from competition for capital, and the tension locks these structures into place (Bourdieu, 1989, 1990; Hilgers & Mangez, 2015). While the exact position of stakeholders will vary based on context, a macro-level analysis is concerned with the general understanding of structures in relation to each other, particularly those participating in UNPRPD programming. Drawing a line to distinguish where concentration of power is locked and located also identifies where it is absent (known as the field of power), framing the complex organizational dynamics prioritized by the UNPRPD mechanism in an explicit way. The aim of inclusive development projects is to see disability not just move into the field of power but become a stable and legitimate structure in close proximity to dominant structures in social space.

The UNPRPD country projects leverage their capital to bring disability into proximity of legitimized structures, potentially stimulating enough capital exchange to promote a sustaining position in the field of power, and secure an influential role in the ongoing operations of local systems.

Assessing the link between structural change and the improved lives of person with disabilities is often difficult to track, emphasizing the importance of exploring the link from individuals to overarching social operations. Rather than suggesting structures are a product of many people, Bourdieu’s theory of *habitus* asserts

individuals embody the structural forces surrounding them, seen through behaviour, disposition, language, clothing and overall presence (Bourdieu, 1984; Calhoun et al., 1993). The individual may therefore function as a proxy of the structures from which they are brought up. This is where programming translates into human rights at the individual level, and in the example of the UNPRPD, realizing the inherent dignity of persons with disabilities. The oppression of people with disabilities reflects what Bourdieu refers to as *symbolic violence*. Topper (2001, p. 43) explains that ‘forms of social misrecognition quietly produce, sustain and legitimate patterns of domination even among those who have no conscious desire to do so’. History and the long-standing exclusion of disabled persons become so inscribed in structures as to be seen as normal and disability as abnormal. The idea of habitus is therefore that individual presentation communicates larger social worth according to the norms reinforced by their overarching social structures (e.g. resume for employment, interviews for higher education, high-end clothing) (King, 2000). These identifiers communicate meaning between people on a daily basis, such as the reaction one might get sharing their occupation of accountant versus a rock musician or the possession of a new-generation iPhone versus a more dated flip phone. Social interaction performs within positionality, and disability is positioned at a great distance from concentrations of power. A baseline of capital is necessary to acquire influential habitus, explaining how the exclusion of people with disabilities at a structural level results in discrimination against persons with disabilities in terms of how they are perceived as individuals (Edwards & Imrie, 2003; Simmons, Blackmore, & Bayliss, 2008). It is therefore essential to address the established structural hierarchy in society as the UNPRPD attempt to do, in order to improve individual lives.

## Mapping Social Space

People with disabilities are recognized as one of the largest minority groups, facing significant marginalization, oppression and systemic exclusion from social participation (WHO, 2016; WHO & World Bank, 2011). This form of inequality – through a Bourdieusian lens – recognizes that disability does not lack inherent value; rather it lacks accumulated capital. Dominant structures operate on one side, and subordinate structures are maintained in opposition, preserving power and status (status quo). An example of subordination in disability can be seen whereby persons with disabilities only participate to the extent their individual modification can conform, and the established norms remain intact. These dynamics can be mapped using ideas established in Bourdieu’s theories by using symbols (e.g. a circle) to represent each structure and their relational architecture. A conceptual map of the global UNPRPD partnership can be schematically presented using a vertical and horizontal axis to represent the composition and volume of capital.

In Fig. 1, relating to the distribution of capital in the UNPRPD programme, we use a small circle to depict low volume and composition of capital and positioned it far from other larger circles (structures with a large volume of capital). A small circle

does not represent the number of people with disabilities, only the relative influence or power in the surrounding social space.

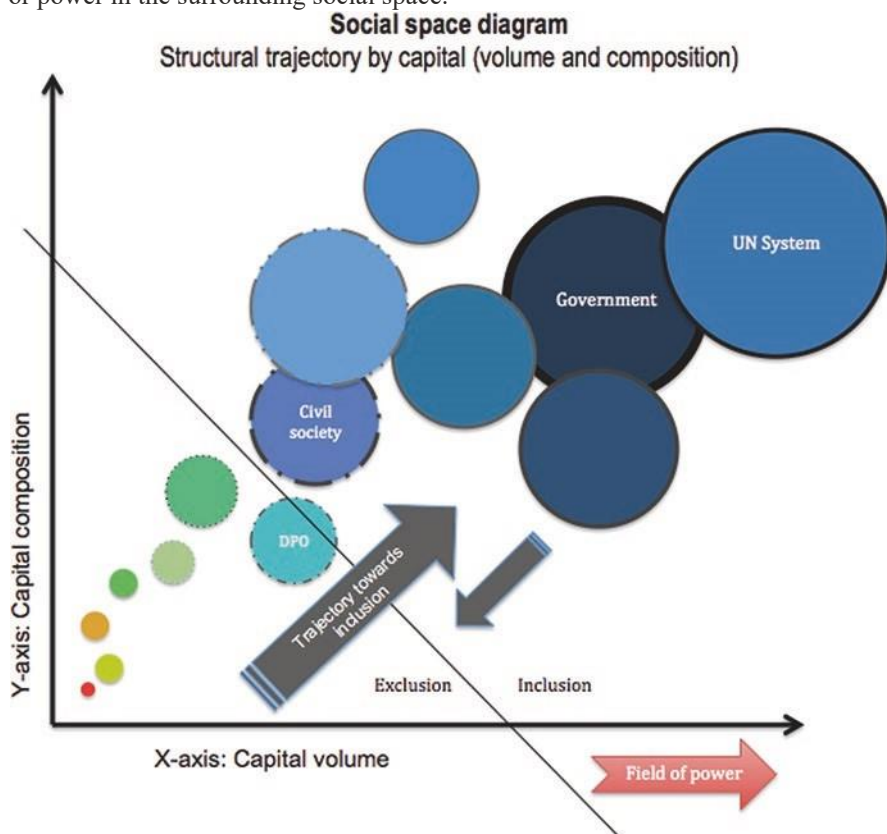


Fig. 1 Diagram of structural relationships between stakeholders in the UNPRPD

The United Nations holds tremendous symbolic capital and translates the larger structural status (and legitimacy of partnering agencies) to the UNPRPD, despite this being relatively new. Encompassing the capital of such an influential institution as the United Nations, as well as the country project programme management, the UNPRPD circle would be larger and in close proximity to other highly powerful structures relevant in any given country project. In the case of a country implementing the CRPD through United Nations Country Teams (UNCTs), the UNPRPD is a central figure disseminating a common framework each project conforms to, strengthening the relationship between structures. The UNPRPD country projects have all four types of capital in the context of implementing the CRPD, whereas the partnering structures often lack the knowledge or prestige to achieve the same results independently.

Larger circles placed opposite to disability will have a similar composition of capital based on their proximity (Bourdieu, 1984, 1987) and can be represented by colour. Bourdieu provides the example of racial disparities and the historical

production of segregated neighbourhoods into separate homogeneous clusters differentiated through bodies by race, but systematically through the embodiment of wealth, education, access to resources and social status when those resources are concentrated within a dominant group (Bourdieu, 1986; Edgerton & Roberts, 2014). Inequality has been transferred to the body as the site of tension for people with disabilities as well (Edwards & Imrie, 2003); however, the manifestation of disability is incredibly diverse and therefore fragments what may have ordinarily formed a cluster into silos within families and communities and across all social fields – see bottom left of Fig. 1. The colour of large structure circles will reflect similar hues, while the disability circle presents a much different composition of capital signified by colour contrast.

Another element to be schematically represented is the ‘legitimacy’ of a structure. When a structure is reinforced over time with wealth, resources, networks and information, it becomes established as normal or, according to Bourdieu, the objectified reality of subjective processes (Bourdieu, 1987, 1990). Many additional structures operate in social space; however for the field describing this study, only structures regularly participating in the UNPRPD mechanism are discussed to express how Bourdieu may be used to highlight development progress across country projects. Major structures vary in their legitimacy. A thick border around a circle can symbolize the durability of a structure, such as government ministries or the United Nations. A textured or fine line around circles can provide contrasting information about the stability of their influence, as structures such as a OPD have only recently become recognized as key stakeholders (United Nations Development Group, 2011; United Nations Development Programme [UNDP], 2016a). These elements are important to capture when mapping out a social field and ideally through repeat analysis as to show increasing stability or the normalizing of disability participation into sustained inclusion.

Figure 1 therefore depicts a diagram of structural relationships found between entities relevant to this research, presented by Bourdieusian theoretical constructs. The *X*-axis represents the volume of capital, where circle size indicates the relative amount of capital. Larger circles have more volume and therefore slide farther to the right compared to small circles towards the left. The *Y*-axis shows the total composition of capital forms (economic, cultural, social and symbolic), where stronger capital diversity moves higher up the *Y*-axis and low capital diversity is captured towards the *X*-axis.

When combining volume (*X*-axis) and composition (*Y*-axis) of capital, the circles take a trajectory, positioning them in social space. The UN System has diverse capital in large amounts (particularly in the context of the UNPRPD project, as they approve projects, manage the project cycle and administer resources); therefore, it moves both up the *Y*-axis and across the *X*-axis, placing the circle in the upper right-hand area in social space. Structures with low volume and composition of economic, cultural, social and symbolic capital (e.g. disability) are positioned in the bottom left-hand corner (red circle) of this diagram.

The colours of circles represent concentrations of similar capital composition, where structures of high status, organizational knowledge or financial resources

share a common shade of blue (for example). When there are large concentrations of one colour, these dominant similarities elicit operational norms over time.

The borders around circles recognize the durability of some structures compared to others in this relational context. The government has contained robust capital throughout history, particularly when compared to the opposing disability structure. By drawing a thick, black line around the government circle, their stability is easily identified.

While there is no distinct dividing line between social inclusion and exclusion, Bourdieu's *field of power* marks an approximate threshold where capital (power) concentrations disperse and therefore overall social influence (lack of financial and non-financial resources) resulting in exclusion. Some structures are well within the field of power, while others are emerging within new partnerships, such as OPDs.

Social space is not static, particularly when development aims to change structural composition and relationships. While the desired trajectory of disability in inclusive development is towards concentrations of power may not be as simple as moving one structure towards others, in other words, this system is interconnected. Social space is relational, and when one moves, others react (Bourdieu, 1984, 1987). One structure cannot be placed into a new position without a shift to the field; therefore the entire space will experience reformation. Circles will expand and contract as knowledge is gained (or lost), networks built (or diminished) and resources increased (or decreased).

As capital is exchanged (e.g. financial resources spent, knowledge transfer, relationships established), circles move along the *X*- and *Y*-axes. The large arrow recognizes excluded structures must move towards the concentration of capital or past the threshold marked in by the field of power. The smaller arrow shows this inherently means the dominant structures will also change their position in social space (Table 2)

**Table 2** Content description of Fig. 1

Structure	Colour (capital composition)	Circle size (capital volume)	Position in social space
UN System	Blue shade	Large circle	Highly stable, large volume and diverse composition of capital
Government	Blue shade	Large circle	Highly stable, large volume and diverse composition of capital
Civil society	Slightly lighter blue shade	Moderate circle	Relatively stable depending on organization, moderate volume and composition of capital
OPDs	Light blue	Small circle	Slightly stable, newly introduced and unrecognized by many development structures, lower volume and composition of capital
Disability	Red	Very small circle	Unstable and excluded, low volume and composition of capital; far in social space to decision-making structures

## Conclusion

While the Force Field Analysis methods of Lewin have been very influential in developing tools for social change, they often depict a social field as being uncomplicated by power relations. By contrast, Bourdieu's social fields are primarily constructed by power relations that are a product of the sort of capital acquired by different social institutions. The empowerment of one group may often require a redistribution of power or at least the opening up of a space where the legitimacy of one group's power can be truly contested by another group. Finding ways to talk about, depict and map these sort of difficult relationships is a first step to acknowledging them and allowing a dialogue between different views. We argue that macropsychology needs to incorporate Lewin-type Theories of Change not only to describe different stakeholder perspectives and resources but also to recognize that such perspectives and resources are imbued with power relations that may influence the possibilities that exist for change itself. Thus the very best of psychological research may not be able to produce social change because it is not in the interest of those who hold power to make such a change. For a sometimes narrow and perhaps sometimes naïve psychological science, this may seem altogether too cynical; but for sociological theorists such as Bourdieu, by contrast, it seems obvious, indeed self-evident. Fortunately these two approaches are not only compatible but also complementary, and their synthesis could greatly enhance the ability of macropsychology to produce social change in the institutions that affect the settings and conditions in which we live our lives.

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# Disability Inclusion and Global Development: A Preliminary Analysis of the United Nations Partnership on the Rights of Persons with Disabilities Programme within the context of the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals

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## ABSTRACT

**Purpose:** *This paper provides a preliminary snapshot of the proposed priorities approved by the United Nations programme designated to support the progressive realisation of the CRPD, the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) outlined by specific Convention Articles and, more broadly, the Sustainable Development Goals (SDGs).*

**Method:** *A content analysis of project proposal summaries approved for funding by the UNPRPD was conducted against the CRPD and SDGs. A matrix of data was produced to draw links between proposed objectives and established international frameworks guiding global development.*

**Results:** *This analysis provides two sets of information. First, a look at the distribution of rights identified in the initial project proposals and accepted by the UNPRPD, establishing a baseline of priorities and outstanding need. Second, it identifies issues that need to be addressed to ensure the advancement of all rights outlined in the CRPD and equitable achievement of the SDGs.*

**Conclusion and Implications:** *Disability inclusion is necessary to achieve the SDGs in an equitable manner by 2030, as well as implement the CRPD. The UNPRPD supports a diverse range of projects spanning many of the*

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*Convention Articles and global goals; however, full participation and scope of disability inclusion requires programming in all areas of both instruments, and this has not yet been fully integrated in the UNPRPD funded project proposals.*

**Limitations:** *This study was limited to the available UNPRPD project proposal summaries that were successful, and did not include all the proposals submitted for consideration. The proposals accepted for funding give insights into the disability inclusive development priorities chosen for project implementation by UN agencies.*

**Keywords:** *capacity, international cooperation, monitoring and implementation, rights, UN agency*

## INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (CRPD or the Convention) is an international treaty which identifies the rights of persons with disabilities, as well as the obligations of national governments to promote, protect and fulfil those rights. The CRPD has been ratified so far by 181 countries. The CRPD is intended as a human rights instrument with an explicit social development dimension (United Nations, n.d.). Disability inclusion is a priority for development due to the extent of exclusion of people with disabilities globally and must be addressed as part of achieving “society for all,” as declared in the 2030 Agenda for Sustainable Development (UN General Assembly, 2015). The United Nations Secretary-General, Antonio Guterres (United Nations Department of Economic and Social Affairs, 2018), highlighted the importance of disability inclusion in the global goals, stating “the Sustainable Development Goals can only be achieved with the full participation of everyone, including persons with disabilities.” Disability inclusion is an essential part of realising the vision for 2030, making the CRPD a vital tool to support global progress.

Working towards a society for all, based on full citizenship of persons with disabilities, the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) is a joint United Nations initiative to advance the rights of persons with disabilities. Understanding the process and priorities of UNPRPD projects is essential to learn about and improve global efforts, as international development policy and programming continue to only partially address disability inclusion (MacLachlan & Swartz, 2009; Gartrell et al, 2016).

## Background

Development projects and programmes implementing disability rights can take a variety of forms. One example is the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). The UNPRPD aims to combine and optimise strengths from partnering entities, including United Nations agencies, local governments, civil society, and additional experts (United Nations Development Programme - UNDP, 2016). It does so by enabling structural changes that progressively fulfil disability rights and enhance capacity building of the individual partners, as well as collaboration between them. As of March 10, 2019, the UNPRPD Multi Donor Trust Fund has supported 39 country projects since its inception in December 2011 (UNDP, 2016) (see Table 1). The UNPRPD works to change normative structures within and across social systems, defined as "... the long-term underpinning conditions that shape social interactions" (UNDP, 2016). Country projects seek to reform the fundamental operations in social life, including actions, behaviours and perceptions that contain exclusionary norms, resource allocation and networks that work in tandem to frame individual experiences through legislative policy and cultural norms (UNDP, 2016). Two examples of structural change processes facilitated by the UNPRPD are briefly described here - one in Armenia and the other in South Africa.

In Armenia, the UN Country Team implemented a new national disability determination model, based on the International Classification of Functioning, Disability and Health or ICF (UNPRPD Technical Secretariat, 2018). This included the shift from medical assessments to a contextualised assessment of disability with social and environmental factors (in addition to the conventional medical assessment), determined with significant inputs from the individuals being assessed regarding their own experience of disability alongside a range of health professionals (UNPRPD Technical Secretariat, 2018). In this approach, clinicians are not the sole decision-makers regarding an individual's disability status; rather, a range of social experiences and environmental barriers are incorporated, reflecting a stronger rights-based model, and may include the presence of a representative from an Organisation of Persons with Disabilities (OPD) during the assessment. Disability determination in line with the Convention underpins the systems that follow disability status, such as accommodations or rights-based healthcare and education.

In South Africa, the UNPRPD programme triggered structural changes through synchronised state policy revisions to ensure the core guiding principles of CRPD

were embedded (UNPRPD Technical Secretariat, 2016). Beyond addressing policy and legislative barriers, the project implemented a Disability Rights Monitoring and Evaluation Framework across government sectors (UNDP, 2016), solidifying the CRPD as a state norm. Thus national level reforms in the process of disability determination in Armenia and disability rights-based policy in South Africa strengthen equal opportunities for full citizenship of persons with disabilities, thus enabling protection, promotion and fulfilment of their rights as enshrined in CRPD and leaving no one behind in attainment of the 2030 Agenda for Sustainable Development.

## Objective

For an overview of the relationship between CRPD Articles and the SDG goals addressed across the UNPRPD global programme so far, this paper presents content analyses of project summaries in terms of the CRPD and the Sustainable Development Goals. Such an analysis provides a preliminary snapshot of the CRPD Articles selected for funding by the UNPRPD in three rounds of projects and the SDGs addressed within the proposal objectives. It also provides an opportunity to reflect on the similarities and gaps found in priorities across proposals that were awarded funding.

## METHOD

**Table 1: UNPRPD Country Projects by Funding Round**

Round 1	Round 2	Round 3
Costa Rica, Indonesia, Moldova, Mozambique, Occupied Palestinian territories, Pacific Island countries, South Africa, Togo, Tunisia, Ukraine, Vietnam	Armenia, Bolivia, China, Egypt, Ethiopia, India, Mexico, Sudan, Tajikistan, Uganda	Benin, Bhutan, Cambodia, Djibouti, Dominican Republic, The former Yugoslav Republic of Macedonia, Guatemala, Malawi, Morocco, Namibia, Nepal, Pakistan, Peru, Serbia, Timor-Leste, Uruguay, Zambia, Zimbabwe

## Data Collection

The data for this study includes 36 of the 39 UNPRPD country project summaries to date, accessed from the UNPRPD Technical Secretariat. Five project summaries were not included in the data from the UNPRPD Technical Secretariat (Djibouti, Dominican Republic, Namibia, Nepal, and Vietnam); however two (Nepal and Vietnam) were located on the MPTF website (2019). Both sources of data were included in the study, leaving only three project summaries from funding rounds 1-3 excluded from this analysis. Each project summary contained 1-2 paragraphs giving context to disability in their respective countries, followed by a short overview of the project objectives. This study analysed only the project objectives and coded deductively based on CRPD Articles 5-33, as well as all 17 of the SDGs. United Nations agencies involved with each project were also listed alongside the summaries, and provided a supplemental analysis of agency participation across CRPD Articles 5-33.

The total number of project proposals submitted to the UN was not known in this data set, nor were the criteria on which projects were selected for funding or declined. While recognising this limitation, the study does not claim to assess the breadth of issues identified in the applications, but only the issues identified in those that were successfully funded over three cycles. This provides the opportunity to look at objectives supported by the UNPRPD programme in line with its stated intentions to “seek to enable structurally focused social action aimed at advancing disability rights, in keeping with the UN Convention on the Rights of Persons with Disabilities” (UNDP, 2016). The proposals approved for funding therefore give an insight into topics supported by the programme and, as this study shows, highlight concentrations of support in some areas outlined in the CRPD, but not all. The projects funded to date also provide evidence of attention to some SDGs, while others are currently not supported by projects selected by the UNPRPD. The authors of the current study acknowledge that the absence of or a low number of projects addressing particular Convention Articles or SDGs, does not necessarily reflect a lower priority for these. It may be that projects addressing such priorities were less well-designed or that the intention is to give these priorities more attention in subsequent programme cycles, or for other reasons. The following section outlines the protocol used to gain a deeper understanding of how the the stated intentions in the UNPRPD programme are delivered in the proposed objectives selected for project implementation.



## Data Analysis

Preparation for analysis began with a general organisation of the relevant coding categories. Cross-cutting Articles 5-9 are also specific rights, and were included in this study to better understand the approach taken by the UNPRPD programme. In the case of Articles 5-9, the rights in question must have been direct programming targets rather than cross-cutting another CRPD right. Articles 5-9 were only counted in this study if the project summary addressed the right as a targeted intervention in programming, e.g., projects implementing the rights of children (Article 7) as opposed to the whole population of persons with disabilities, or systematic accessibility interventions (Article 9) rather than a principle cross-cutting substantive rights as a secondary outcome. In this way, projects that improve systems of education without a direct reference to how the proposal intends to implement the diverse rights of children with disabilities were only marked in Article 24 for the right to education. Although children are a primary recipient within the system of education, the subject for intervention was education.

Monitoring and implementation Articles 31-33 were also included in this study with a similar logic. States parties' obligations for progressive realisation of the CRPD have actionable items that align with the UNPRPD programme structure. Statistics and data collection, international cooperation (e.g., projects targeting ratification of the CRPD) and state monitoring and implementation, all involve actions eligible to be categorised in this study.

Articles 1- 4 were not included, as they are cross-cutting principles applied throughout the Convention, including: purpose, definitions, general principles and general obligations (CRPD, 2006). These provide the landscape for the Articles that follow, and are not specific targets for development. In other words, Articles 1- 4 are not mutually exclusive from the subsequent rights; rather, they are inherent to the specific rights used in this study to match the primary outcomes in project proposals. Furthermore, Articles beyond 33 involve procedures between States and the Committee to the CRPD, and final provisions (CRPD, 2006). The UNPRPD programme aims to address the Convention between duty bearers, rights holders, the UNCT and other experts (2016), limiting the scope of this analysis to Articles 5-33. While acknowledging that analysis of other articles in the CRPD may be instructive, it was beyond the scope of the current research.



## **The Convention on the Rights of People with Disabilities - CRPD**

The UNPRPD country projects are written in the language of the CRPD, so the coding process resembled matching pairs. Articles were seen as whole coding categories, even when some project objectives only reference part of the Article components. For example, the country project in Armenia addresses Article 25 (right to health) by establishing a disability determination assessment to be implemented nationwide (UNPRPD Technical Secretariat, 2018). Reform of disability determination by medical professionals to a rights-based model addresses the right to health; however, it does not address the cost of services in Article 25(a) or location of service provision listed in Article 25(c). Alternatively, some project summaries had limited detail, as is the case of Togo stating health was targeted, with no additional information. In both of these summaries, Article 25 was marked on the data matrix. This categorical approach followed through the entire analysis, providing an assessment of manifest content in project summaries.

Data was organised in Microsoft Excel, by country project on the vertical axis and categories (CRPD Articles or SDGs) on the horizontal axis. Each item occupied a single cell, where an individual country project could be followed by row across all categorical columns from left to right. This format could also highlight the frequency of programming by Article or goal. For example, the UNPRPD as a global development programme can be seen to have substantial contribution to SDGs 10 and 17 (reduced inequalities and partnerships for the goals), with a substantial programmatic commitment within those categories. Each country was listed in order of funding round (round 1 countries in alphabetical order, followed by rounds 2 and 3), displaying the change in priorities over time. Each project summary was critically analysed for programming objectives, and individually placed in the corresponding categories.

## **The Sustainable Development Goals (SDGs)**

The CRPD outlines the human rights to which people with disabilities are entitled, that are the same rights afforded to all people as they are rooted in the United Nations Universal Declaration of Human Rights (UNPRPD, 2016), nesting the Convention within a system of larger directives. There is synergy between these documents and the SDGs, as they all provide direction for global progress across populations. Disability inclusion and the SDGs are often discussed in terms of the disability-specific indicators that set the 2030 goals apart from the Millennium

Development Goals (MDGs), which had no direct mention of disability (United Nations, 2011). Disability development is still development, and this matrix steps outside the disability-specific lens and compares the UNPRPD programme to the systems it is embedded in. The cooperation between documents allowed for an additional content analysis of the same units (UNPRPD project objectives) against the SDGs.

The same procedures used to analyse the 36 UNPRPD project summaries with reference to the Articles of the CRPD were applied to coding based on the 17 SDGs. Project targets were screened with the United Nations General Assembly SDG resolution document (2015) to fully understand each goal against the project objectives. The same project objectives were coded to the 17 goals as whole categorical units, rather than to isolated targets and indicators. Formatting design remained the same, and were placed in a separate Microsoft Excel sheet.

Each CRPD Article or SDG was treated as an independent category for coding the project summaries. The Articles were then analysed according to type: cross-cutting principles and specific rights, substantive articles, and monitoring and evaluation based on the Convention framework. For analysis of the CRPD, basic addition and division were used to show the frequency and percentages of UNPRPD project targets in a specific Article or category of Articles by the total number of project targets. For example, the total number of project targets identified in the country summaries accepted for funding were 178. Based on that total, the data shows which type of CRPD Articles are more frequently addressed in the selected projects. Between the cross-cutting Articles 5-9, substantive Articles 10-30 and monitoring and evaluation Articles 31-33, the total number of project targets in each category are roughly similar. Furthermore, the number of project targets found in each category were divided by the number of Articles in each category. The 66 targets between 5 cross-cutting Articles versus 58 targets in 21 substantive Articles then throws light on the concentrations of development initiatives found in selected UNPRPD country projects.

Articles 10-30 accounted for 33% of the total data in 21 rights, with a particularly high concentration of data in 4 specific Articles. In this case, a percentage was also taken for the number of project targets in Articles 24-27 within substantive rights to discuss the notable frequency in these four topics.

The SDGs were treated as whole categories and grouped into clusters of data based on frequency in UNPRPD country project summaries (see Figure 3).

In general, UNPRPD project summaries were found in clusters of zero, few, moderate and high frequencies of data. These groups, particularly the SDGs not found in UNPRPD programming, are discussed in the following sections.

## RESULTS

The projects supported by the UNPRPD are a vehicle for national disability development work aligned to one global framework, resulting in a range of contributions to development goals in both the CRPD and the SDGs. This section presents findings from the content analysis of the UNPRPD project summaries against the CRPD Articles 5-33 and SDGs. Importantly, the SDGs yet to be addressed in project proposals supported by the UNPRPD programme are identified. Finally, this section presents the UN agencies selected to participate in the proposed projects and the frequency of engagement between each specialised agency.

### The CRPD

The results of the CRPD matrix show a strong concentration of work in the cross-cutting, monitoring and implementation Articles, and Articles 24-27 of the Convention. The 5 cross-cutting Articles accounted for 37% of the data points found in UNPRPD project summaries. 30% of the data accounted for three Articles (31-33) of the Convention for monitoring and implementation. Of the 29 CRPD Articles included in this study, 33% of project targets addressed the 21 substantive Articles. Furthermore, 71% of those targets in substantive Articles (33% of the total) were found in four specific rights (Articles 24-27). Additionally, many Articles of the Convention are not evident in the UNPRPD project summaries (see Table 2). The distribution of data (both data absence and concentrations) present a pattern of development activities approved for funding.

**Figure 1: Frequency of CRPD Articles targeted by UNPRPD programming**

CRPD article	36 UNPRPD country projects																																				Total
Article 5																																					16
Article 6																																					13
Article 7																																					12
Article 8																																					18
Article 9																																					7
Article 10																																					0
Article 11																																					0
Article 12																																					2
Article 13																																					3
Article 14																																					0
Article 15																																					0
Article 16																																					6
Article 17																																					1
Article 18																																					0
Article 19																																					1
Article 20																																					0
Article 21																																					2
Article 22																																					0
Article 23																																					1
Article 24																																					11
Article 25																																					11
Article 26																																					6
Article 27																																					13
Article 28																																					0
Article 29																																					1
Article 30																																					0
Article 31																																					10
Article 32																																					16
Article 33																																					28

### Cross-cutting Articles 5-9

After categorising the data, a total of 66 project targets were located in CRPD Articles 5-9. The data found that 16 country projects (of the 36 in this study) target equality and non-discrimination as described in CRPD Article 5. Awareness-raising was the most frequent cross-cutting right targeted in 18 country projects. Both Articles were present in all three rounds of country projects. Article 6, addressing women with disabilities, was seen in 13 of the UNPRPD projects identified in funding rounds 1 and 3, without mention of Article 6 in the 10 country projects from round 2. Children with disabilities were targeted in 12 projects and found across all funding rounds. Accessibility was least prevalent, evidenced in 7 project summaries.

### Monitoring and Implementation Articles 31-33

Monitoring and implementation of the Convention are a priority for UNPRPD programming based on the Strategic and Operational Framework (2016) to institutionalise a partnership between local governments and local experts (e.g., OPDs, civil society) to ensure the rights of persons with disabilities are realised with the support of the United Nations. The UNPRPD initiative is evidenced in the data, with 78% of country projects focusing on national implementation. Article 33(3) of the CRPD (2006) highlights the role of persons with disabilities

and OPDs in national implementation and monitoring, and is prioritised in the UNPRPD projects aimed at building local capacity within OPDs and between these actors and government entities for progress and accountability.

International cooperation (Article 32) was targeted in 16 UNPRPD country projects, primarily in rounds 1 and 3. Round 2 had only one project focused on aligning the national frameworks to the CRPD. Many projects worked locally to develop a National Disability Strategy, but were not explicitly assessed against the international CRPD standards. A few projects also partnered with other international NGOs such as Humanity and Inclusion or other international or regional experts, resulting in a total of 44% of projects targeting Article 32.

Finally, Article 31 recognises the importance of statistics and data collection to enable effective use of the Convention (CRPD, 2006). About 28% of UNPRPD country projects target data collection and improved capacity to generate and use disability-specific data in policies and programming.

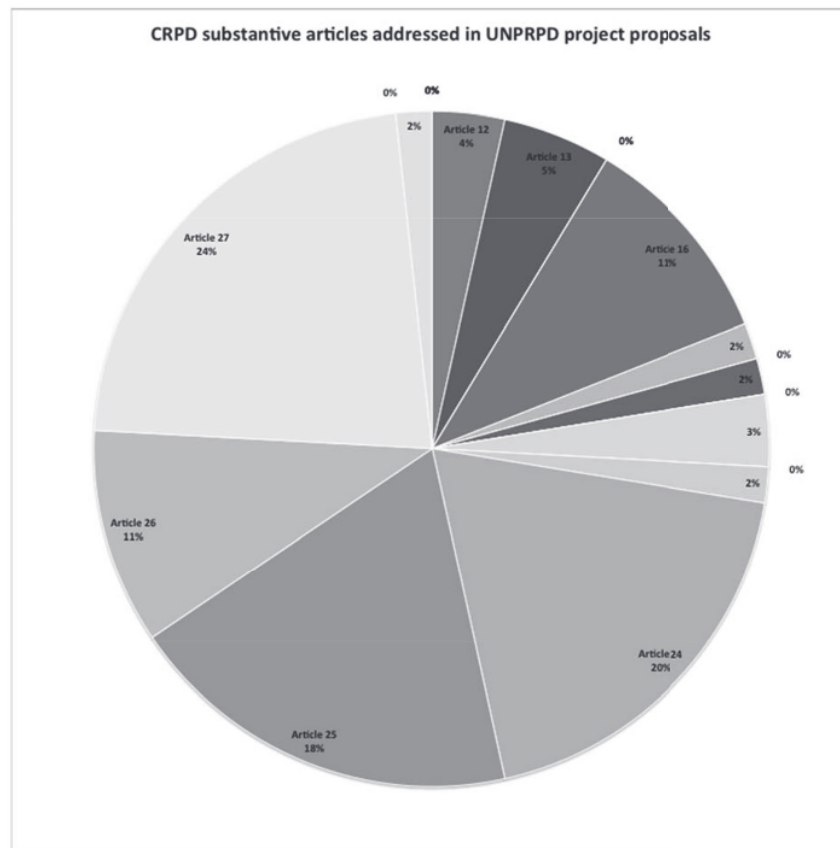
### **Substantive Rights and Obligations**

Substantive rights in the CRPD include both civil and political rights, as well as social and cultural rights specific to a disability context. Of the 58 substantive rights addressed, 71% of the data fell within 4 Articles. CRPD Articles 24-27 relate to education, health, rehabilitation and employment, and work. The next most frequent project objective fell under Article 16 - freedom from exploitation, violence and abuse. All 6 projects targeting violence were specifically aimed at reducing gender-based violence (GBV). These data were categorised in Article 16 rather than Article 6, as the interventions listed were specific to violence (gender-specific violence is articulated throughout Article 16), rather than women as bearers of a broad range of rights, including freedom from violence. As shown earlier (see Methods), this is an example of Article 6 as a cross-cutting principle as well as a specific right.

Figure 2 shows the percentages of CRPD substantive rights found in the approved UNPRPD project proposals. Of the 58 data points in Articles 10-30, Articles 16 and 24-27 are most frequently supported by the UNPRPD projects, and many Articles are not currently in programming.



**Figure 2: Percentage of each Substantive Right found in CRPD Articles 10-30 from approved UNPRPD project proposal summaries**



Nine CRPD Articles were not found in UNPRPD project proposals. All Articles not yet addressed in project proposals were substantive rights, covering a diverse range of topics including right to privacy, risk and humanitarian emergencies, and participation in cultural life, recreation, leisure and sport among others listed below in Table 2. Many of these rights lack available research but are however known barriers, such as adequate standard of living, to the inclusion of persons with disabilities. While the UNPRPD project summaries used for this study represent the starting point for various projects, identifying the rights that are recurrent and absent from United Nations programming provides a better understanding of which rights were supported for funding and which remain less supported or unsupported. Concentrations of rights supported by the UNPRPD across country contexts does not determine global priorities, though it is worth noting that the UNPRPD is one of the largest disability initiatives to progressively implement the CRPD, and their selected priorities are located in a broader network of influence within international development.

**Table 2: Articles absent from UNPRPD project proposal summaries**

<b>Articles absent from UNPRPD project summaries</b>
Article 10: Right to life
Article 11: Situations of risk and humanitarian emergencies
Article 14: Liberty and security of person
Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 18: Liberty of movement and nationality
Article 20: Personal mobility
Article 22: Respect for privacy
Article 28: Adequate standard of living and social protection
Article 30: Participation in cultural life, recreation, leisure and sport

### **Sustainable Development Goals (SDGs)**

The UNPRPD programme promotes several of the SDGs, with a strong emphasis on specific goals. The underlying premise of the UNPRPD programme is to engage new or strengthen existing partnerships, primarily between government entities and OPDs (UNDP, 2016). The data supports a partnership approach taken by the UNPRPD, evidenced by 22 country projects targeting interventions aligned with SDG 17. Capacity building among civil society and representative organisations of persons with disabilities for the purpose of partnership with government entities and decision-makers are prioritised among the country project summaries in all funding rounds, and found in SDG 17.18 regarding data, monitoring and accountability (UN General Assembly, 2015). Similarly, the capacity of government institutions to appropriately address the rights of persons with disabilities outlined in the CRPD were captured in SDG 16. It is worth noting that while the summaries did not discuss the capacity building and institutional strengthening of the UNCT, the participation of the United Nations teams within this UNPRPD partnership approach are likely affected by programming as well.

National legislation reviews were very common in the UNPRPD project summaries aimed at reducing existing structural barriers in policy and legislation for persons with disabilities. These data were categorised under SDG 10: reduced inequalities. SDG 10.3 states, “Ensure equal opportunity and reduce inequalities of outcome, including by eliminating discriminatory laws, policies and practices and promoting appropriate legislation and action in this regard”

(UN General Assembly, 2015). Twenty-six country project summaries explicitly work to address legislative barriers. SDGs 10, 16 and 17 were the most frequently addressed goals in UNPRPD programming.

Goals addressing more concrete topics such as health, education, work and gender equality were evident in moderate frequency, much like the cross-referenced CRPD results. In particular, many of the participating United Nations agencies are focused on specialised topics, such as the International Labour Organisation (ILO) to decent work, World Health Organisation (WHO) to health and well-being, UN Women to gender equality, and UNICEF to education. Established technical expertise aligned with specific SDG goals were apparent in all three funding rounds of UNPRPD programming.

Few project proposals directly targeted SDG 1: poverty, SDG 9: industry, innovation and infrastructure, and SDG 11: sustainable cities and communities. Many of the goals in this data cluster are important for realising the rights in the CRPD, such as assistive technology, public spaces, and access and affordability of communities. With less than five UNPRPD country proposals addressing these goals in the initial summaries, additional research is needed to better understand current efforts.

Several SDGs were absent from UNPRPD country project summaries used for this study. Environmental goals are not represented, which provides reason to continue researching the connection between disability and their surrounding context beyond the built environment. Hunger and clean water and sanitation (SDGs 2 and 6) are not seen in approved proposals to date, despite the evidence available to link disability with the repercussions of disproportionate poverty affecting people with disabilities globally (World Health Organisation & World Bank, 2011). Furthermore, the goals absent from UNPRPD project summaries have a reinforcing relationship to the SDGs targeted with the lowest frequency (see Figure 3), including SDG 9 (industry, innovation and infrastructure), SDG 11 (sustainable cities and communities) and SDG 12 (responsible consumption and production), highlighting an opportunity to mainstream disability rights and inclusion throughout the SDGs. Figure 3 categorises the number of UNPRPD projects targeting various SDGs in programming.



**Figure 3: Frequency of SDGs targeted by UNPRPD programming**

Sustainable Development Goals	36 UNPRPD country projects																				Total
SDG 1	■																				1
SDG 2																					0
SDG 3	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	12
SDG 4	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	14
SDG 5	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	11
SDG 6																					0
SDG 7																					0
SDG 8	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	13
SDG 9																					2
SDG 10	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	25
SDG 11	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	4
SDG 12																					0
SDG 13																					0
SDG 14																					0
SDG 15																					0
SDG 16	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	26
SDG 17	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	22

**Table 3: UNPRPD country project objectives by SDGs**

Number of UNPRPD projects	SDGs represented
Few (1-5 data points)	SDG 1: No poverty SDG 9: Industry, Innovation and Infrastructure SDG 11: Sustainable cities and communities
Moderate (10-15 data points)	SDG 3: Good health and well-being SDG 4: Quality education SDG 5: Gender equality SDG 8: Decent work and economic growth
High (20-30 data points)	SDG 10: Reduced inequalities SDG 16: Peace, justice and strong institutions SDG 17: Partnerships for the goals
Zero projects targets	SDG 2: Zero hunger SDG 6: Clean water and sanitation SDG 7: Affordable and clean energy SDG 12: Responsible consumption and production SDG 13: Climate action SDG 14: Life below water SDG 15: Life on land

The Danish Institute for Human Rights (2018) has highlighted the value of examining the interaction between the Articles of the Convention and the SDGs.

Disability is referenced in multiple parts of the SDGs, specifically in the parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and the monitoring of the SDGs. Tebbutt et al (2016) have illustrated how Assistive Products are relevant to the equitable and inclusive achievement of each of the SDGs. Having noted that some SDGs are not addressed by approved UNPRPD project proposals, Table 4 provides some idea of local projects by the unmet global goals and corresponding CRPD Articles. The examples provided include persons with disabilities in addressing barriers, and offer a starting point to include new objectives to programming, both at the Convention level and global SDG framework.

**Table 4: Disability Inclusion applied to SDGs absent from UNPRPD project proposal summaries**

SDG 2: No hunger	CRPD Article 28: Adequate standard of living and social protection	<p><i>Application:</i> Persons with disabilities live in disproportionately high rates of poverty, and access to employment, communities and accommodation resources (e.g., personal care attendant) affecting food security and levels of nutrition (UNDESA, 2018).</p> <p><i>Example:</i> As of 27 February 2019, the ADA National Network and Grassroots Gardens of Buffalo websites highlight universal design techniques in community gardens, promotion of inclusive public space, increased access to food, stress reduction and community engagement for persons with disabilities.</p>
SDG 6: Clean water and sanitation	CRPD Article 28: Adequate standard of living and social protection  Article 32: International cooperation	<p><i>Application:</i> Disability accessible latrines and clean water in public spaces will reduce environmental barriers that prevent individuals with disabilities from engaging in their communities, and increase awareness among community members without disabilities.</p> <p><i>Example:</i> Development projects in Uganda and Zambia led by WaterAid initiated a community-driven programme for accessible latrines and sanitation, resulting in increased access to public spaces and community awareness, in addition to the development of an inclusive standard for local WaSH projects (Wapling &amp; WaterAid, 2014).</p>

<p>SDG 7: Affordable and clean energy</p>	<p>CRPD Article 28: Adequate standard of living and social protection</p> <p>Article 32: International cooperation</p>	<p><i>Application:</i> Exclusion from schools and public spaces, and increased rates of poverty, mean that households with an individual with a disability are more often lacking heat or have increased exposure to poor air quality from burning inefficient fuels indoors (UNDESA, 2018).</p> <p><i>Example:</i> A solar-powered wheelchair has been designed and proposed in Bangladesh to promote an affordable alternative to power chairs for increased access to individuals with mobility disabilities, and low environmental impact (Sakib et al, 2015).</p>
<p>SDG 12: Responsible consumption and production</p>	<p>CRPD Article 9: Accessibility</p> <p>Article 21: Freedom of expression and opinion, and access to information</p> <p>Article 24: Education</p> <p>Article 27: Work and employment</p>	<p><i>Application:</i> Individuals with disabilities face barriers to participating in market production, including skills and opportunity to engage in sustainable production.</p> <p><i>Example:</i> An NGO in Serbia called Udruženje Naša Kuća, or Our House, recognises that individuals with developmental disabilities who lack legal capacity are left out of critical sectors including vocational training and employment. The organisation serves as a day programme to provide technical training in a variety of production skills such as making chocolate flavoured from fresh fruits and herbs from the gardens on side or eco-friendly cardboard bins and boxes and pressed paper for wedding invitations. Members of the organisation become part of an environmentally conscious approach to production, and skills training for meaningful participation in market activities (<a href="https://www.facebook.com/nasa.kuca/">https://www.facebook.com/nasa.kuca/</a>).</p>
<p>SDG 13: Climate action</p>	<p>CRPD Article 9: Accessibility</p> <p>Article: 10: Right to life</p>	<p><i>Application:</i> Individuals with disabilities are at an increased risk during climate-related emergencies due to lack of standardised preparedness or evacuation strategies (Handicap International, 2015; UNDESA, 2018; Wolbring &amp; Leopatra, 2012).</p>

	<p>Article 11: Situations of risk and humanitarian emergencies</p> <p>Article 21: Freedom of expression and opinion, and access to information</p> <p>Article 24: Education</p>	<p><i>Example:</i> Malteser International and the Community Empowerment and Resilience Association (CERA) (2017) implemented visual early warning systems for deaf or hard of hearing individuals in Myanmar, increasing a sense of belonging within their local communities and reducing vulnerability in the event of a disaster.</p>
<p>SDG 14: Life below water</p>		<p><i>Application:</i> Over three billion people depend on marine and coastal biodiversity for their livelihoods. Impacts of coastal pollution on childhood disabilities and adverse outcomes for pregnant women (Rahman et al, 2012).</p> <p><i>Example:</i> Projects that aim to sustainably manage and protect marine and coastal ecosystems from pollution involving women with disabilities (recycling). Waste Aid project example - in The Gambia, to capture plastic waste in the coastal town, training in plastics recycling will be offered for women, young people and people with disabilities (Citation-<a href="https://resource.co/article/wasteaid-wins-funding-plastics-recycling-project-gambia-12958">https://resource.co/article/wasteaid-wins-funding-plastics-recycling-project-gambia-12958</a>)</p>

SDG 15: Life on land		<p>While there are no explicit articles within the CRPD to address how SDGs 14 and 15 are relevant to the fundamental rights of persons with disabilities, disproportionate levels of poverty (WHO &amp; World Bank, 2011), food insecurity (UNDESA, 2018), community reliance on agriculture and marine industries, and climate affects on disability (Groce et al, 2011; Wolbring &amp; Leopatra, 2012) all link these SDGs to disability development. Farming for health (di Iacovo et al) and disability on farms (Mohan,1987; Whelan et al, 2009; Gómez-Marín et al, 2004; Field &amp; Jones, 2006; Deboy et al, 2008) are of significance, thus a role for agencies like that of UN Environment Programme and International Fund for Agricultural Development do exist in future rounds of UNPRPD programming.</p> <p><i>Example:</i> Green care farms in the United Kingdom are found to support individuals with learning disabilities in an accessible and holistic way, while promoting vocational skills and environmental awareness (Rotheram et al , 2017).</p>
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## UN Agencies

Each project summary lists participating United Nations agencies, which were cross-matched with Articles 5-33 of the Convention. These agencies are seen to work together as “One UN” (UNDP, 2016); therefore each agency was tallied as participants on all targets evidenced in the project summary. Tasks may be delegated during implementation to respective agency specialisation; however this analysis looks at the country project as a unit, including all agencies enlisted to contribute. Additionally, the UN agencies were listed by funding round with the number of projects affiliated with each agency (see Figure 3) to see trends as the UNPRPD programme launches new project cycles. The analysis of UN agencies only includes the 34 country projects sent from the UNPRPD Technical Secretariat due to lack of available data for the remaining 5 country projects.

**Figure 4: Frequency of UN agency affiliation in 34 UNPRPD Country Projects by Funding Round**

Agency	UNPRPD Funding round (34 of 39 country projects)														
	Round 1				Total	Round 2				Total	Round 3				Total
UNICEF	█	█	█	█	8	█	█	█	█	8	█	█	█	█	7
UNDP	█	█	█	█	7	█	█	█	█	5	█	█	█	█	9
WHO	█	█	█	█	7	█	█	█	█	4	█	█	█	█	6
ILO	█	█	█	█	7	█	█	█	█	3	█	█	█	█	4
UN RC	█	█	█	█	5	█	█	█	█	4	█	█	█	█	2
UNFPA	█	█	█	█	4	█	█	█	█	2	█	█	█	█	10
OHCHR	█	█	█	█	3	█	█	█	█	2	█	█	█	█	4
UNESCO	█	█	█	█	2	█	█	█	█	5	█	█	█	█	5
UN Women	█	█	█	█	1					0	█	█	█	█	7
UN Habitat	█	█	█	█	1					0					0
UNV	█	█	█	█	1					0	█	█	█	█	2
UNESCAP	█	█	█	█	1					0					0
WFP	█	█	█	█	1					0					0
FAO	█	█	█	█	1					0					0
UNIDO					0	█	█	█	█	1					0
Egypt ICT TF					0	█	█	█	█	1					0

UNICEF was documented to participate in more Convention Articles than other agencies across the UNPRPD programme, followed by UNDP. Of the 178 total project targets, UNICEF is affiliated with 104, and UNDP is participating in 92. The next most affiliated agencies are UNFPA and WHO. The ILO, UNESCO, Office of the Resident Coordinator (UN RC), UN Women, and OHCHR were all moderately affiliated with projects, ranging from 42-62 of the 178 project targets. Disability development crosscuts fields of expertise and supports the partnership approach of the UNPRPD; however it is important to explore how agency specialisation interacts with disability-inclusive development. While the programme aims to support projects based on local need, many of the project objectives align with UN specialisations (also see Figure 2). Further research is recommended to better understand the relationship between UN agency specialisation and the priorities receiving funding from UN programmes. The remaining agencies were affiliated with 15 or less project targets, often involved with just 1-2 country projects.

UN agency participation changed across funding rounds. This was especially noticeable with UN Women, going from one project affiliation in round 1 to seven projects in round 3, and was not listed in any of the round 2 projects. This trend in UN Women supports the data from CRPD Article 16 focusing on GBV, found only in round 3. Additionally, the lack of environmental project targets aligns with the lack of UN agency affiliation with an environmental specialisation. Finally, OHCHR was affiliated with 9 country projects of the 34 available in this part of the study. As technical expertise guides various UNPRPD interventions, stronger representation from the agency specialised in human rights instruments may further support implementation of the Convention in more diverse ways.



## DISCUSSION

Despite global consensus around disability exclusion and the wide-ranging barriers to social inclusion, not all rights and priorities outlined in the CRPD and SDGs have been fully embraced – so far - within the UNPRPD country proposals selected to launch projects. There are trends in projects accepted for funding by the UNPRPD, whereby certain rights and goals are heavily supported, and others are absent from all three funding rounds. The lack of environmental targets outlined in project proposals supported by the UNPRPD programme parallels the acknowledged lack of data and lack of focus around these issues, as also found in other types of reviews (The Danish Institute for Human Rights, 2018; UNDESA, 2018). Environmental sustainability cannot be done without people with disability, and disability rights cannot be realised without access to a healthy planet. Thus this research recommends future calls for proposals to address environmental aspects that respect, protect, and fulfil related CRPD rights and that are closely linked with SDGs.

The data from the funded applications from 39 country projects suggests that thus far they have not been inclusive of all rights or goals. Approximately two-thirds of proposals focused on legislative reviews, capacity building and partnerships proposed by individual UNCTs. Having more project proposals originating from outside the UNCT, or in closer collaboration with local actors, may enhance the diversity of applications.

It is important to consider where disability is positioned in international development, particularly from a large programme such as the UNPRPD. The evidence from project proposals shows a pattern (20-30 data points) that focuses on SDG 10: reduced inequalities, SDG 16: peace, justice and strong institutions, and SDG 17: partnerships for the goals. Future calls for project proposals could address CRPD Article 28, adequate standard of living and social protection, with a focus on SDG 2: zero hunger, SDG 6: clean water and sanitation, and SDG 7: affordable and clean energy. Further research on project trajectories over time will shed light on patterns that evolve. The programme has introduced the stronger presence of UN Women, incorporating gender as a priority in the most recent funding round. However, participation of OPDs in the development and implementation of the projects should also be enhanced. A recent survey carried out by International Disability Alliance (2020) indicates that among OPDs in 13 out of the 25 countries where UNPRPD projects were operational, 60% of them were aware of the UNPRPD and 100% of those who were aware of them were consulted on the projects only to ‘some extent’.

This paper has sought to report disability inclusion in development programming within the UNPRPD programme. The programme has many laudable achievements and it is understandable that certain Articles and goals should predominate during earlier project cycles. In the next stages of the programme it is suggested that focus can be given to some additional and emergent issues. For instance, how is the experience of disability a driver to achieving the global goals and rights-based programming? How can incorporating disability into environmental development facilitate greater progress towards implementing the CRPD and achieving the SDGs? How can development practices innovate new approaches to achieving disability inclusion beyond the established scope of specialised agencies? Further research and reflection will continue to support the pursuit of these questions; however this assessment hopes to offer some insight from one approach to disability development seen in the UNPRPD programme.

## CONCLUSION

Disability inclusion is necessary to achieve the United Nations SDGs and the implementation of the CRPD. The UNPRPD supports a diverse range of projects spanning many of the Convention Articles and global goals. Increasing the scope of the programme will allow it to address areas of both instruments. This broader scope could be a feature of future funding calls within the programme. Future research should continue exploring the progress of disability rights as a result of the UNPRPD country projects, with a view towards full implementation of the CRPD and achievement of the SDGs. Such research may include an assessment of country need against the project priorities selected; project outcomes and impact; the role and extent of participation between the United Nations agencies, government and civil society- particularly Organisations of Persons with Disabilities (OPDs); how the results from country projects inform the evolution of the UNPRPD programme; and the power dynamics involved in project planning, trajectories and outcomes.

### Limitations

The authors stress that the UNPRPD country project summaries are not a comprehensive account of the work done in each country and only represent the proposed priorities accepted for support by the programme. The data set used for analysis reflects only what was made available to them; it did not include rejected project proposals, or the criteria on which selections were made. Additionally,



the UNPRPD programme quite legitimately seeks to support project targets that address local needs (UNDP, 2016), which may not be captured in the CRPD Articles or SDGs, and so were not analysed in this study. Future research could include a similar analysis between the UNPRPD project objectives supported for implementation and the States Parties and alternative reports to the Committee on the Rights of Persons with Disabilities, list of issues and concluding observations. Such an analysis may provide further insight into the project selection process and the extent to which priorities are selected based on UN agency specialisation versus local need. The issuing of the call for project proposals only through UN channels may need to be reconsidered so that government and civil society are able to participate at the entry stage on an equal footing.

The project proposals used for this study were written and submitted before the inception phase and may not represent the objectives put into action. As projects were accepted and planning began between partnering entities, the stated objectives may have evolved. This limits the possible interpretation and meaning that can be derived from the project proposals. It may well be that projects continue to develop new objectives in subsequent funding rounds to build towards progressive realisation of the CRPD; that is not captured in the study results. Ongoing and detailed project summaries would provide new information to expand this analysis. Despite the acknowledged limitations of the data used in this study, it nonetheless serves as a preliminary snapshot from available information, to report on important development efforts underway to implement disability rights in diverse country contexts.

One important point to distinguish is the UNPRPD programme's stated goal of enabling the advancement of disability rights in line with the CRPD, and it does not claim to advance all rights evenly (UNDP, 2016). The project proposals all evidence the advancement of rights found in the CRPD, however they are concentrated by priority topics. The purpose of this research is to take a step back and look at the UNPRPD programme as one mechanism deployed to address the known barriers facing people with disability around the world, especially structural barriers. While the data used for this study cannot speak for the efficacy of actual project implementation, it does offer a critical analysis of the proposed objectives that got through to the funding stage. This reflection brings to light considerations for setting future objectives in disability development efforts, the procedures by which priorities are selected, and areas of disability rights that may benefit from more focused action.

Finally, while this paper seeks to report on the priorities set by different projects, there is awareness that these priorities occur within a deeper political context, power struggles within the UN, and broader political economy of international development efforts that impact the selected objectives for UNPRPD projects. Such topics are beyond the scope of the current paper, but are the focus of ongoing research (ALL Institute working paper, 2020).

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# Implementing ‘real’ change: a Bourdieusian take on stakeholder reflections from the United Nations Partnership on the Rights of Persons with Disabilities project in Uruguay

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## Abstract

This study aims to illustrate the process of implementing a national disability project targeting structural change facilitated by the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD), and analysed through the theoretical lens of Pierre Bourdieu. This paper presents qualitative case study findings from interviews with key representatives from the UNPRPD country project in Uruguay in 2019. Participant responses were coded and analysed using Bourdieu’s definitions of field, doxa, capital, habitus and hysteresis as a framework to understand complex inter-institutional experiences. Findings indicate a significant shift in cultural capital within government ministries and United Nations agencies. Immersion into a paradigm of disability rights and programmatic doxa established by the UNPRPD altered fundamental aspects of participant habitus, creating a mismatch between internal and environmental conditions. Furthermore, shifts in political power created concerns about what constitutes ‘real’ change, and increased the disruption between habitus and perceptions about the UNPRPD project achievements.

**Keywords** Bourdieu · Disability · International development · Hysteresis · Uruguay

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## Introduction

Disability rights have been a growing development consideration, particularly, since the United Nations Convention on the Rights of Persons with Disabilities (CRPD) entered into force in 2007 and the World Bank (WHO & World Bank 2011) reported approximately 15% of the world's population having one or more disabilities. Global recognition of the historic and persisting exclusion of persons with disabilities was a significant shift in perceptions of disability. Constructions of disability are commonly framed in the medical and social models. The medical model understands disability as an individual deficit that requires intervention (e.g. cochlear implants and speech therapy for D/deaf people) to fit 'normal' social expectations, whereas the social model recognises the diversity of human beings excluded through barriers in the build environment (e.g. buildings without ramps, policies for institutionalisation, absence of alt text in digital images) that have systematically excluded people with disabilities (Shakespeare 2014). People with disabilities were once seen as a small group invisible to the majority. Now international treaties set out global calls for rights on behalf of disabled people and other marginalised groups.

Much of the CRPD mandates more than reducing physical barriers such as installing a ramp or elevator, but also deconstructing the ideologies and abstract barriers that perpetuate the discrimination of persons with disabilities in spite of previous efforts to improve accessibility. The United Nations established a joint programme to support countries navigating the complexity of disability development, comprised of various UN entities (nine participating agencies at the time of this study, including ILO, OHCHR, UNDESA, UNDP, UNESCO, UNFPA, UNICEF, UN Women and WHO) into the Partnership on the Rights of Persons with Disabilities (UNPRPD) (United Nations Development Program [UNDP] 2016). The barriers addressed in UNPRPD programming target established norms expressed through policies, practices, attitudes and beliefs about individual capacity maintained over generations, and are very difficult to reform. Changing the fundamental assumptions on which the structure of our societies is based will help to create a ripple effect. For example, reforming the way in which people with disabilities are educated will likely impact employment, civic participation, healthcare and other central structures extending from improved access to education. The UNPRPD approach to implementing the CRPD aims to address these underlying barriers across multiple contexts, thereby triggering structural change beyond a contained, predetermined development scheme.

The structural change initiated by UNPRPD country projects are diverse in their approaches to realising disability rights in local contexts, offering valuable experience and insight into how this global issue can be addressed. Sociologist, Pierre Bourdieu, provides a framework to make sense of the UNPRPD initiative and disability inequity, as well as methods to express structural changes in complex organisational systems. The study below applies Bourdieu's research methodology to explore the UNPRPD mechanism from the United Nations Country Team (UNCT) perspectives in Uruguay during the first phase of programme implementation.



The UNPRPD Theory of Change (ToC) follows a tripartite framework, engaging the United Nations, government ministries and civil society organisations (with particular emphasis on Organisations of Persons with Disabilities; OPDs; previously called Disabled Persons Organisations or DPOs) (UNDP 2016). By bringing entities together that historically work independently, the UNPRPD takes the strengths and expertise from multiple UN agencies, diverse government ministries and the representative organisations of persons with disabilities into human rights development. As of 2020, the UNPRPD has supported 39 country projects, 3 regional projects and 7 global programmes (UNPRPD 2019).

## Bourdieu and the UNPRPD

Bourdieuian theories have been used to describe a number of social inequalities, including disability (Bryne 2018; Edwards and Imrie 2003; Blackmore and Hodgkins 2012) and situations of international development (Krause 2014, 2017); however, they have rarely been used together. Bourdieu's theories focus on the systems level and how structures interact in context (Bourdieu 1987). Each level (macro and micro) is inseparable, whereby either structure or agent always leads back to the other, and therefore must be seen as a whole.

Bourdieu describes marginalisation at the systems level and how structural barriers are embedded in individuals (*habitus*), reinforcing exclusion through practice as social norms (Bourdieu 1984, 1986). Structures at the hierarchical top are held in place by disproportionate resources such as knowledge, social networks, status and economic stability (*capital*), whereas exclusion occurs when those resources have been historically withheld (Bourdieu 1986). The UNPRPD looks to trigger these underlying forces (*capital*) that perpetuate exclusion at the structural level, making Bourdieu a natural fit to ground the findings in a systematic context.

Bourdieu's theories encompass several key concepts valuable for understanding disability development locally and globally, including *doxa*, *fields*, *capital*, *habitus* and *hysteresis*. First, the idea of everyday norms and assumptions or *doxa* (Bourdieu 1977) is important to explore the way structural processes are practiced by individuals in their social 'bubbles' that perpetuate inclusion or exclusion. *Doxa* describes shared logics that have become institutionalised as automatic or natural practices (Bourdieu 1977, 1998). These practices are constrained to their contexts, making various *doxa* unique unto themselves. *Doxa* is a common consideration for international development because a successful intervention in one country may not translate to another. Local experts, such as community members or civil society organisations, can help ameliorate the consequences of development in unfamiliar settings by bringing local logics to development projects. The norms and conventions, or 'rules of the game' according to Bourdieu, are practices developed and fixed by repetition throughout history (Bourdieu 1977). These local constructions are so ingrained that they become a saturated and stable system over time, and may be experienced as the objective reality underlying subjective practices—as 'just the way things are' (Bourdieu 1990).

Second, *field* is a setting where individuals and their social positions are located, and they contain site-specific doxa (Hilgers and Mangez 2015; Thompson 2014). The field from this study is the UNPRPD country project in Uruguay, and primary players include the partnerships between the UN, government, civil society and consultancies working to change the surrounding national context. Each of these entities contains their own reality, making each perspective valuable to initiating change across social systems. Programme partners are micro-systems within their larger contexts, such as the UNCT as a substructure under the umbrella of the larger UN system. The government ministries involved are rooted in the larger political atmosphere. DPOs extend from the larger context of civil society and their particular mission (e.g. specialisation within disability organising). The UNPRPD country project becomes a field once these entities come together for one shared purpose, with varying degrees of autonomy.

Partnering structures are intended to have low levels of autonomy from their broader affiliation mentioned above, but remain highly autonomous in their UNPRPD partnership role. Civil society or an OPD is selected to act as a channel to the larger disabled population that it represents. Likewise, the UNCT acts as an extension of the larger UNPRPD framework, as the UN operational system. This is not to say these external influences are simple and fit neatly into programming relationships. Structures represent groups with varying familiarity and, particularly with OPDs, a history of oppression. In other words, this UNPRPD field operates inside the broader fields of international development and those associated practices or hierarchies, the Uruguayan political field and the broader field of disability exclusion (Wescott, et al. In press) beyond the participants in this study.

*Capital* refers to the specific forces that direct power, particularly the historical and durable exchanges of resources (often between entities with similar capital value) that maintain hierarchies and norms across a given field (Bourdieu 1986). Bourdieu states that the processes between structures are defined by capital exchanges, and the capital transactions determine the difference between structures that position social hierarchies (Bourdieu 1986, 1987). That is, more capital leads to more powerful positions, and the absence of capital is associated with low influence and therefore little power behind the forces directing social systems. Social research categorises capital into various forms: economic, social, symbolic and cultural (Bourdieu 1986). Cultural capital is further divided into several sub-categories: *institutionalised* capital, which refers to the concrete qualifications of power, such as a driver's license or college degree ('she went to Harvard'); *objectified* capital, which refers to objects that contain meaning and status, such as designer shoes ('she dresses like a Harvard woman'); and *embodied* capital, which refers to understandings, opinions or ideological views expressed through particular attributes of personality, skills or voice held by individuals and groups ('she sounds like a Harvard woman') (Bourdieu 1986). The possession of these types of power relate to the ability to instigate, track and understand structural changes that underpin social systems. People with disabilities have experienced barriers to education, which results in high unemployment (United Nations n.d.). In this small example, the withholding of cultural capital acquired by formal education leads to a lack of economic and social capital generated from affiliation to legitimate institutions. These barriers are



reflected in population data worldwide. The lack of capital over time perpetuates systematic exclusion from meaningful participation in social life. Capital provides a framework to understand the initiation of capital exchange between hierarchically opposite structures in the UNPRPD country projects.

The experience of the individual must be viewed in relation to structural forces and therefore is best understood through Bourdieu's *habitus*. Bourdieu captures much of the intangible barriers to inclusion through habitus, seen as the reflection of history through individuals and the intergenerational transmission between social structures and social life (Bourdieu 1990; Edwards and Imrie 2003). The individual is considered an embodied representative of their surrounding structural values, attitudes and behaviours (Bourdieu 1984), and therefore a conduit to structures targeted for development. Habitus can be highly nuanced for each aspect of the person including country of origin, educational background, family structure and innumerable other variations. However, what matters in the case of this research is the UNPRPD approach to include key representatives from each partnership as proxies to their larger structural embodiment, relying on individual habitus to initiate meaningful change.

This research was interested in the changes made in all key theoretical areas as a result of the UNPRPD project's efforts to positively enhance disability rights. While Bourdieusian concepts are not static, the concept of *hysteresis* ties together the experience of change in the habitus–structure relationship. Habitus and structures are malleable and can be sensitive to significant change in one side but not the other. Hysteresis is defined as the disruption to an individual's experience when internal (habitus) and external (structures, doxa) states become misaligned. (Bourdieu 2000; Hardy 2014; Strand and Lizaardo 2016). Based on the UNPRPD approach to engage key people within large systems and expose them to disability rights, hysteresis helps to understand how participants make sense of their experience in the UNPRPD project and what it means for their structural affiliations. More broadly, the concept of hysteresis is instrumental in making sense of a rapidly changing world comprised of structures that do not change at the same pace of the populations it serves, and will be relevant for future social research.

## Project background

The UNPRPD project in Uruguay had three primary lines of work or, as the project termed them, 'pillars' of work. The first pillar focussed on universal access to health (CRPD article 25), specifically access to sexual and reproductive health in young people with disabilities. The second worked to address Gender-Based Violence (GBV), supported in CRPD articles 6 (women with disabilities) and 16 (freedom exploitation, violence and abuse), primarily through research and improvements to the national GBV intake protocol. Finally, the project set out to gather baseline data and map out services available to persons with disabilities (CRPD article 31: statistics and data collection). After the project was well underway, the project provided additional support to a working group of seven different government institutions towards developing a common disability assessment system, rather than the seven

different assessments currently in use. Further, the UNPRPD seeks to increase the capacity of all stakeholders by establishing working relationships between government and civil society beyond the project.

The United Nations and Uruguayan government representatives have a long-standing relationship in development. Several participants joked that the country is so small that the two institutions often swap the same people and share a strong familiarity between practices. Learning the 'rules of the game' was very different for the civil society organisation selected to represent people with disabilities in Uruguay. The Alianza (also called the Alliance), an umbrella organisation of parents of people with disabilities and service providers (at the time of interviews, there were no OPD member organisations), operates on a voluntary basis, and does not have sufficient funding to offer salaries or formal positions. Many of the representatives work a full-time job in addition to their organisational role. This key difference in structural composition will be explored further in the discussion section.

## Methodology

Initiating structural change is difficult, particularly, when the roots of disability exclusion are built into the fabric of social life. The aim of this research was to engage with individuals tasked with making change, and ask which events resulted in a significant shift towards realising the rights of persons with disabilities as a result of the UNPRPD project. A qualitative case study methodology provides a rich and varied context, which aligns with the UNPRPD programmatic framework to address local needs (UNDP 2016). Semi-structured interviews with the Most Significant Change Technique (MSCT) used open-ended questions to generate targeted reflection, while breaking away from traditional milestone-based metrics. All interviews were conducted during a field study visit in June 2019 at various locations in Uruguay.

The MSCT, which was created to capture data across different roles in complex organisational programmes, has proved useful in disability-inclusive development (Davies and Dart 2005; Quilliam and Wilson 2011). The use of MSCT to generate narratives across stakeholder groups allowed for standardised interviews, despite the differences between groups. Each participant answered the same six questions, generating insights from their respective organisational perspectives.

Four categories of stakeholders were interviewed in this study: UNCT representatives, government officials from participating ministries, organisations within the civil society organisation selected to support the UNPRPD project, and hired consultants. Purposive sampling was the most appropriate approach to ensure all participants had some role in the UNPRPD project. For example, the case study was not open to all civil society organisations or those promoting disability rights; rather, the inclusion criteria limited sampling to only organisations engaged with the UNPRPD work in this study. The same is true for government and UNCT participants. Government representatives from ministries outside the scope of the project were excluded from this study, as well as UN representatives. All stakeholders engaged in the project met the inclusion

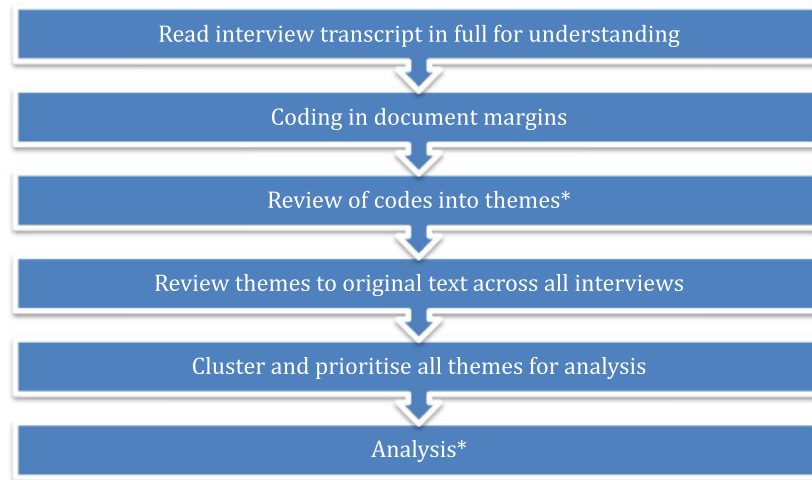
criteria, meaning that the sample only featured participants who could speak with insight and authority on the relevant project. All participation were voluntary and scheduled with the support of the UNPRPD project coordinator on site.

After all interviews were conducted, the data were analysed using Interpretive Phenomenological Analysis (IPA). The primary aim of IPA is to derive meaning from individuals' perceptions of a given phenomenon as evidence to make informed claims about the phenomenon itself (Smith et al. 2009). The UNPRPD programme operates globally, while also being flexible enough to address local instances of disability exclusion. Each country project is a different phenomenon, unique to that particular country's context and specific needs of people with disabilities. IPA, while criticised for its overdependence on subjectivity of interpretation, aligns with the purpose of including stakeholders that represent distinct expertise and experience related to local disability exclusion. As seen in Bourdieu's structural positionality and theories of capital-driven divides, stakeholders were chosen based on their autonomous affiliations to bring their perspectives together, bridging the gaps between groups. Based on the UNPRPD programme design, IPA analysed the meaning and context of individual responses, keeping in mind diverse perspectives of each structure. In this study, a subjective interpretation was necessary to faithfully represent each participant from their stakeholder perspective rather than analysing for concrete or objective statements.

The critique of researcher subjectivity in IPA was recognised in preparation to analyse the data. Smith et al. (2009) provide strategies for analysis to increase rigour and reduce bias. IPA involves researcher interpretation while calling for the data to be handled in a way that works to preserve the meaning in participant interviews. Thus, IPA provides a general protocol to process and handle data by first reading the transcripts in full for clear understanding, coding interviews for themes, connecting the themes as they relate to each other and repeating with all interview transcripts in the same fashion before proceeding with the analysis (Smith et al. 2009). Interpretation of participant responses takes place at only two points in the data-handling process: identifying themes and conducting the written analysis. Accordingly, this research implemented the method following IPA recommendations (see Fig. 1).

### **Coding and themes**

Each interview was coded as a single case, beginning the process of coding and thematic identification anew with each of the interviews. Most participants discussed the same issues from various perspectives, laying the foundation to identify the emergent themes. Themes were easily determined by the synergy between the different actors and their reflections on the project. In this way, even though reading the 20th interview made clear which themes were emerging as significant in line with the trends of the previous 19, the later interview was still analysed in full in order to unearth any additional themes.



**Fig. 1** This figure shows the stages of data handling for each interview transcript; stages 3 and 6 (each marked by an asterisk) indicate points in data handling with researcher interpretation

## Findings

### Interview responses

Few participants shared a complete story in response to the MSC central question. Many described the conditions of the project, along with challenges or their reflective thoughts on change and improving the lives of people with disabilities. In response to the interview prompt, ‘From your point of view, describe a story that illustrates the most significant change that has resulted from the UNPRPD project in Uruguay at this phase of implementation’, participants ranged from declining to answer, describing the challenges and sharing positive aspects of the project; only 4 of the 22 participants offered a complete story. The word ‘change’ was met with reservations on the part of participants and created a sense of caution around claiming concrete change. Many participants evaded specific statements concerning change when answering the question by making vague comments such as, ‘We have made a big step’, ‘major contribution’, or ‘we have some key achievements’ while also reporting the need for ‘real change’.

Nearly all participants gave mixed reactions during the interview. For example, PG5 said:

If this ends up being plans that never end up being implemented – it can be positive, or it can be very, very negative. It can generate expectations. Then if later you want to implement something like this, people won’t trust you. Have to implement at least some of the objectives, at least enough so people can trust you.

Moreover, the same participants expressing frustration in response to one prompt would provide hopeful or positive project feedback to a different prompt later in the interview. Likewise, some participants answered the prompts with

thoughts about positive change, but they later shared concerns and unmet expectations. Based on the trend in participant responses, the interviews were analysed for themes across the whole conversation rather than scrutinising answers to any given question in isolation.

Participants generally felt the project had strong objectives and the UNPRPD approach to programming was valuable; however, change was difficult to identify or commit to. PG3 shared, '[That is a] really difficult question—not yet. I think we are in the point in the process of wrapping up, but there is nothing—I would love to hear what other people have said'. PUN16 from the United Nations articulated their response to change, saying, 'That is not the objective of the project—that has to be expressed as improving access to disabled people, but we all know, in 18 months, we will not be able to implement the change'. Similarly, PG10 who had discussed many positive aspects of the project during the interview, the topic of change was still tentative:

The project in the UN has helped with the sexual and reproductive health, concepts for diagnosis, training – but it doesn't cover the more specific aspects... We made theoretical progress without having real things to offer – like rehab in health. Can have all the theory, it is not only about the technical support.

Alternatively, change was described more broadly as seen from PCS7, who noted, 'This is a cumulative thing. I'm not sure if there is an event, but the whole set has positioned the topic of disability in the public agenda'. Each of these participants from a range of structural perspectives shared contributions and achievements of the project. However, many of the interviewees answered the questionnaire by offering their overall reactions to the project in place of a story.

The subsequent interview questions respond to the story of change that the participants initially identified. In the absence of a story, these queries became a tool for participants to reflect on and describe their experiences and reactions. Interestingly, while change was difficult to identify when prompted directly, participants were much more comfortable discussing the significance of the project. Based on participant responses, what the project actually did was establish the problem, engage actors with personal and professional growth, and increase the visibility of disability rights.

Many participants reported the significance to be personal, despite not considering their own paradigm shift as 'real change'. PUN14 described how the project has influenced her daily operations and access considerations:

For me, it was a milestone. It was like, before and after. I think even, I am used to working in the frame of human rights, and the stories that she had (in the inception activity), and shared with the audience. It really touched me. This was the initial milestone. Other parts of the project that touched me – I will show you (shows her new business cards with Braille text)... Now I make my cards, thinking about persons with disabilities. It is a small detail, but that – that is the way this project touched me, I changed some part of my life – my cards. This is the personal change I have made.

Later, she described how this change in individual behaviour became structural: ‘For the first time, I had to be very sincere. For the first time, we at the office rethink about the issues that our public events, for example, if they were accessible for everyone’. PUN17 reflected,

As personal experience, I learned a lot about persons with disabilities and how to act when you are, we have... all my instinctive actions are not always right. With blind people, I have to talk and not just act. That has increased my capability to have relations with persons with disabilities.

Many participants reported a change in their perception along with destigmatisation, even normalisation of disability in daily life. While these individuals were all from the United Nations or government structures, the participants did not always recognise themselves as agents of change with a new paradigm, despite their position as key stakeholders.

The magnitude of disability exclusion is overwhelming for any individual structure to resolve. Many of the government actors assigned to multiple projects addressing disability rights shared a feeling of loneliness or burden of carrying the depth of work required to achieve ‘actual change’. The UNPRPD approach recognises the cross-cutting nature of disability rights and has worked to bridge individual silos for some participants, providing an empowering view of their role as agents of change and strategic planning. Thus, PUN14 stated:

If you look at the project, you could think ASSE (Administration of Health Public Services) would only participate in Theme 1, but it participates in all 3. So maybe that wasn’t the objective of ASSE to participate in all three, but now we realise we are important actors in the project, because we will be incorporating it into our administrative records for our services. If this happened outside the project, we would not have been a part of the project. Or would have done it a different way.

The challenges facing individual focal points for large, powerful structures are present in the participants’ reflections, particularly the investment in becoming more aware of disability rights. PUN14 later shared a beautiful sentiment: ‘I think that people are—human beings are sensitive. The same that happened to me, perhaps in a different intensity, but all the people who were elected into this project. It is like a start point’. Fundamental changes to key actors were as present in participant responses as project reflections reporting no change, highlighting the discrepancy between changes actors sought to engage, and becoming the subject of change as a project outcome.

### **Stories of change**

Few participants provided stories in answer to any of the MSCT questions. Four stories were collected in response to the UNPRPD project, and one additional story about another disability-related project. Two of the four UNPRPD-related



stories described the inception event and the power of having persons with disabilities tell their own stories to an audience of government and UNCT members. PG3 said,

It is so very few times that persons with disability were heard, and have the chance to speak to government officials, to public, policy makers, and we created an environment. That was something that we – that gave these people the chance to think or be confronted with exclusion or with a different image. One girl was talking about all her achievements, and that helped break barriers of the vision of disability that is current. Charity and that. But I think that moment was very moving... It was a big ceremony and everyone was listening. So it was worth the risk. That doesn't change the life of anybody, but that was something. It was important.

Exposure to disability rights and engaging with key people were common themes across all four stories. Another story described a workshop held in Argentina with Mitch Loeb from the Washington Group, attended by some of the individuals assigned to the UNPRPD project. PUN8 said,

I think it is an activity representative of this need to join all the people working on – about – person with disability policies. They were open, they showed that they were open to hear about one possibility. They've known for 3, 4, 5 – 10 years about the Washington Group questions, but to go to discuss and go with an open mind. And try to reach a consensus. This process for trying to reach a consensus is just a great advance. To put them to dialogue, and to include the civil society voices is just a great advance. So I think that activity – the Washington Group activity was one of these key activities that showed this open mind, this perspective to work with the others.

The dialogue mentioned in this example was a key theme identified across all 22 interviews. The process of accumulating engagement across key individuals towards a common goal struck most participants as facilitating, or the first step towards 'real' change. The conversations between partnering structures were not an immediate win, but they did resonate with participants as significant. The fourth story demonstrates the importance of intergroup dialogue:

PC22: Yesterday I had a meeting with the women's institute that has always been uncomfortable with some questions. But I think it was the first time that some data were shared and put on the table so we can think together about the best strategy – and they are interested in the outputs of this work to be included in the national plan to make public policies – apart from having national data. I do believe that after working with the focus group, there is a well-known professional here in Uruguay that works on child abuse and trafficking, that after the focus group, she said to us, "Now I cannot unsee what I have now seen". There have been movements within people that when we share real situations of the weaknesses, the feedback we get from them, it's like – ok let's get together to find the best way. I think even though it may seem like something small, I think that some situations are being put on the agenda that had no vis-

ibility in the past at all. I do believe there is intention and political will to think about how to go about it. I don't know when, but at least we do have the will.

Many participants felt the UNPRPD ToC, engaging key people in diverse structures towards effective state-wide change, was a successful approach to the project. Dialogue was said to have led to political will and hopes for change in the future. This hope was challenged by the changing values towards a new government across Uruguay and is discussed in detail below.

### Political changes

Although Uruguay experienced political stability for 15 years prior to the UNPRPD project, it faced unexpected risk to its political stability during the elections in fall 2019. After the Broad Front established a leftist government that lasted from 2004 to 2019, elections returned power to the National Party after a narrow two-part vote on 27 October and 24 November 2019 (The Economist 2019). Participants' reflections of the UNPRPD project and identifying changes were affected by the unknown outcome to the elections four months prior to voting. Key project actors were unsure if the government participants would continue in their post or be replaced by a new government the following year. PG3 reported, '[There is a] real risk all the hard work they have done stays in a limbo. Risk of having to do it all over again'. Change felt possible but vulnerable to the political climate, as suggested by PUN8: 'Maybe it could be—will be used to improve the public policies. I am speaking conditionally because there will be the election in October/November, so we don't know who is taking in this key input'. Thus, political changes created uncertainty regarding the future implications of the project.

Several participants shared their support for structured engagement and dialogue as a pathway to realising disability rights in Uruguay, however, they also recognised several limitations once the political position of government partnerships was under threat of change before the project's end.

Participants from across the project said,

PC22: We are just a few people, but everyone is very protective of their own territory. So being able to think together, and these new spaces and figures that are painful, but I think this at least left this stage ready to start thinking. Since I've joined, it has made progress and in some ways gone back. Some data was heard, and other cases were pressured for the data to be public. I think now we can start thinking about doing something about this. It is a very complicated year for the country. I don't know if it was the best time to do it (the project), since in October we have elections. And that makes people feel unsure.

PG5: If this ends up being plans that never end up being implemented – it can be positive, or it can be very, very negative. It can generate expectations. Then if later you want to implement something like this, people won't trust you. Have to implement at least some of the objectives, at least enough so people can trust you.



PUN3: Maybe we can make this other government be a part of this, and own the project – (it is) high risk.

PUN17: We think we are on the way. But the change of government is... everything.

Further concerns over solidifying the project to withstand the broader political changes altered the perception of the project's achievements. PUN14 said, 'We don't have the solutions, but at least we started the awareness'. PG20 stated, 'What I would like in this project in the remaining time, our own project becomes more visible—make the impact more visible—so people get to know about it—we need to have made a difference'. The project achieved not only the objectives laid out in the project proposal, but also made strides towards a systematised disability determination assessment across key sectors. While the project followed through on the targets set during its inception, participants broadly felt the mission had not been achieved. Activities such as research, trainings and established connections around a common framework began to feel insufficient as the political climate changed over the project's duration. Many participants commented on the distinction between 'theory and practice'. PG5 stated,

Regarding the other projects, we still don't have an output that is used in practice. We don't have anything in practice yet. The only thing I can think of, GBV, consultants gave information about how it is conducted at a national level. So, we have done some work, but still a lot to be done.

Nearly all participants hoped for some concrete and durable changes to withstand the possible change in government, which was an unforeseen consideration at the time of project planning.

## Discussion

Interview data from the UNPRPD project in Uruguay are discussed below through the lens of Bourdieu's theories.

### Capital and context

Bourdieu's capital, or the underlying forces driving social dynamics, is a tool to interpret the stakeholder interactions and processes designed to ignite structural change by the UNPRPD. The group held meetings in various government or United Nations buildings, around a conference table, scheduled at regular intervals and followed formal agendas, reflecting an unprecedented dedication to the topic of disability rights. Bourdieu recognised the significance of this type of legitimised procedure as the creation of opportunity (Moore 2014), and thus advantage over unstructured, unsystematic interaction prior to the UNPRPD engagement and programmatic framework. In line with the theory, several participants saw the value of formality in the same way Bourdieu described, noting the process of solidifying disability development conversations within places of national authority led to 'putting disability on

the agenda'. Further, the processes took place around what Bourdieu notes as meaningful objects (objectified capital), such as grand conference tables in a government building reserved for project participants to sit around and engage across stakeholder lines. Bourdieu's connection between abstract and tangible is seen in the UNPRPD partnership building, which is difficult to capture in traditional metrics. For example, the Alliance had no physical space to conduct operations. This lack of objectified capital, or tangible resources that facilitate or hinder participation, contributed to the quality of engagement between the Alliance and the UNPRPD tripartite approach. These contrasting examples are helpful to see how objectified capital according to Bourdieu can help or hinder the processes underlying the UNPRPD project goals, evidenced by the meeting rooms as a means of establishing connection that is so essential to the partnership approach. In other words, the presence of cultural capital struck participants as a noteworthy step towards establishing disability rights as a legitimate agenda item for the business conducted in government and UN buildings.

In addition to the impact of physical space and formal procedure in the project, Bourdieu's field theory makes sense of the landscape where capital was mobilised. Thompson (2014) relays Bourdieu's work, stating: 'Like a force field, a social space operates semi-autonomously. It is a human construction with its own set of beliefs, which rationalize the rules of field behaviour—each field has its own distinctive "logic of practice"' (p. 68). From the data, participants often reflected on the establishment of a metaphorical 'seat at the table' for focal points who previously worked in silos. Bourdieu's shared understanding behind field-specific practice is called *doxa*, distinct from other fields that participants may interact with. As such, each focal point was there on behalf of the broader government ministry, UN agency or population of people with disabilities, and solidified a new set of norms comprising structural proxies. The UNPRPD established a formal protocol to include a range of stakeholders and gain consensus among members for project activities, always guided by the CRPD as their compass. While government focal points remained positioned in their governmental role throughout the project, discourse and decision-making procedures were open to all stakeholders while in the UNPRPD context. The project scheduled an onboarding period to ground all institutional representatives in the disability rights paradigm and establish expectations for project conduct emphasising the engagement of persons with disabilities. Much like Thompson described, the UNPRPD was an intentional construct, with field behaviour guided by the specific belief in the CRPD. The production of a sub-field for project interactions was reinforced by scheduled recurring meetings, exposing and normalising the consensus approach to participation regardless of their affiliating position. In other words, the partnership approach initiated a Bourdieusian sub-field to have legitimised discussion around disability rights in the Uruguayan context.

Establishing a sub-field created the opportunity for engagement, however, capacity issues with the selected civil society organisation altered the role of people with disabilities in the project, resembling an objectified capital (or tokenism) of those who were available to the project. While the programme design called for equal partnership between rights holders and duty bearers (UNDP 2016), the lack of OPD membership throughout the process changed the utility of the few individuals with disabilities engaged in the project. Interview responses remarked on the significance

of personal testimonies by those individuals with disabilities in the inception activity and health training sessions, particularly, the rare opportunity for high-level government officials or health providers to see and hear from successful individuals with disabilities. These select few conveyed the ethos of the UNPRPD project to outsiders through their physical presence, or as objects for paradigm shift (cultural capital). This can also be seen as symbolic capital on behalf of the UNPRPD, where the project conveyed the presence of a regulatory partnership many participants felt did not meaningfully exist. Whether seen as objects or symbols, disabled bodies were reclaimed in public spaces to advocate for rights, while the internal operations lacked meaningful OPD membership within the Alliance.

Embodied cultural capital requires ongoing, direct exposure to a new set of ideas or norms to integrate into one's habitus (Bourdieu 1986), illustrated by the UNPRPD establishing a sub-field with consistent reinforcement of the disability rights paradigm. This creation of a new field and new 'rules' (or doxa) with prolonged exposure made the participants acutely aware of the constructed social dynamics that resulted in and perpetuate disability exclusion in Uruguay. The shift from regular exposure to embodiment can be seen in the government and United Nations participant responses describing a fundamental change in practice, a fresh start, or a new-found conviction. PG19 said, 'I've been working on this for more than 30 years... It was difficult to talk about this, but now it is difficult to stay silent'. Many participants shared this shift from disability invisibility to self-driven advocacy in the same way Bourdieu described the construction of new internal (habitus) and group (doxa) norms through direct exposure. As such, the UNPRPD group dynamic created a circular reinforcement whereby individual paradigm shifts were regularly reinforced by the project environment.

Many participants discussed disability rights issues beyond the UNPRPD project. Several focal points on the project were also assigned other tasks related to disability as a central expert in their structure. This experience enabled what the UNPRPD calls 'duty bearers' (United Nations Development Programme 2016), or individuals with the capital to action programming, to immerse themselves in a new worldview and become more oriented towards disability inclusion. In a sense, this reorientation of their perspectives made it feel as though disability was suddenly everywhere. The majority of participants reported a sense of urgency in achieving change and addressing the barriers imposed on people with disabilities, and they even expressed the intention to address such issues beyond the scope of the projects they were working on. This deeply embedded change in habitus is further evidenced by their unsuccessful attempts at applying practices from their previous habitus into the field of the UNPRPD: 'We feel impotent trying to find the real mechanism to give them a voice and protect and empower them. It's hard'. The notion that a *real mechanism* did not include any of the long-held processes signified the presence of a new, shared habitus for participants in the same way Bourdieu recognised the possibility of individual change to such an extent that a habitus begins to mismatch their newly acquired internal and well-established external states, challenging the implementation of a new normal (see *hysteresis* below).

Based on the data, the project did not reach persons with disabilities in the single phase of programming as a primary outcome. Going back to the social model

of disability, what the project did was reorient powerful actors towards a disability rights paradigm rather than changing (e.g. fix, alter, assimilate) individuals with disabilities. This outcome has positive implications for sustainability, as embodied capital alters the lens through which people practise in the positions they occupy. Byrne (2017) argues the value of this internal shift by placing it within the context of Bourdieu's theory of habitus. She states, 'Even when the dominant cultural arbitrary (social construction of disability inequality) is challenged, it will not be until the habitus of the non-disabled population is effectively transformed via the internalisation of "new" dispositions that we will see substantive change' (p. 12). The data provide evidence of a shift in habitus by the non-disabled representatives from dominant structures in the UNPRPD (though not the Uruguayan population), despite the majority opinion that 'real' change has not been achieved.

The final of Bourdieu's capital considers the economic distribution, and specifically the impacts of uneven distribution of resources between groups. In this case, the costs involved with civil society involvement was challenging for historical reasons. Bourdieu discussed the ease of interaction when a relationship is cultivated with ongoing resource exchanges over time (Bourdieu 1986), which was seen in the United Nations and government's long-standing working relationship. Salaries and approved lines of work were budgeted within the organisations to account for the time required for participation in weekly meetings and project activities (economic capital) without supplementing with direct payment for each focal point's time. This was not true of civil society, which lacked a mechanism to support the cost of participation, creating a demand for voluntary commitments from individuals in addition to their income-earning jobs or care responsibilities. Using Bourdieu's terms, the economic power between dominant structures protected the individual actor's role in project participation while supporting the cost of that contribution, however, that was not true of the most subordinate structure. Small grants were available for project expenses but did not reach far enough to fund salaries or the 'meaningful participation' outlined in the CRPD. Participation on 'equal' volunteer terms is inequitable based on vastly different capacities between structures, and created a barrier over time between the UNPRPD sub-field interactions 'at the table' and engagement with the member body of the Alliance.

### Habitus reconstructed

Research has provided ample support for the concept of habitus. That said, the literature addressing mismatched habitus is far harder to find. Bourdieu's concept of *hysteresis* captures a mismatch in individual habitus and their field or social space of interaction (Bourdieu 2000; Hardy 2014). According to Dirk and Gelderblom (2016, p. 345), 'the habitus can adjust to new conditions, but that this adjustment has limits... hysteresis results when the habitus is affected by fundamental change in the field'. As previously described, habitus and structure are interdependent and relational. The currently available research describes a mismatch in a singular way: a static habitus confronted with a changed environment (Barrett 2018; Bourdieu 1990; Dandoy 2015; Dirk and Gelderblom 2016; McDonough and Polzer 2012).

Nonetheless, this research evidences the same phenomenon in reverse. In the case of Uruguay, a new habitus was formed among participants to a disability rights paradigm, situated in the same overall national context from which they developed their previous habitus. In Bourdieusian terms, the project became a space to practice their newly acquired dispositions without a tremendous mismatch between habitus and the UNPRPD project sub-field. Everyone in the project contained the same, newly developed sense of disability rights that was not evidenced in broader society. Many of the participants felt a mismatch in habitus to their 'home' structures (e.g. government ministries, medical offices, schools), which had previously held more synergy.

Although a change in environment did occur in silo by establishing the UNPRPD as a sub-field, participants remained officially affiliated to their respective structures while contributing to the project (autonomous). As evidenced by interview responses, the project was highly valued despite the frustration for 'real change'. From a Bourdieusian lens, the UNPRPD was a mini-field, temporary and constructed, shared with a group over a common doxa and thereby matching their new habitus to their environment. They collectively constructed their group and norms around the rights of persons with disabilities. Bourdieu noted the culture shock experienced by individuals when they step outside of their environment of shared understanding and into social systems that do not align. For UNPRPD participants, their home structures did not undergo the same transformation, and those internal changes were not in practice across systems in Uruguay. For Bourdieu, the larger government ministries and UN agencies would have adopted the same paradigm shift and priorities of the UNPRPD with little friction in implementing disability rights across the country to avoid hysteresis. While Bourdieusian methodology does not provide a distinct habitus threshold, or tipping point from one set of norms and beliefs to another, previous research has attributed similar reactions to fundamental change as those experienced by the UNPRPD focal points (e.g. Barrett 2018; Graham 2020; McDonough and Polzer 2012).

The adoption of a new reality—one where the exclusion of persons with disabilities is recognised as an objectively true by product of society's social constructions—was evident in participant responses, such as '... all the people who were elected to this project. It's like a start point'. Having undergone a paradigm shift towards a disability rights perspective, participants gained a new vision for the future of Uruguay. Bourdieu theorised about habitus integrated deeply as to be automatic and frame that individual's disposition and conduct (Bourdieu 1990). Disability rights were deeply embodied with no evidence of nostalgia for the participant's previous norms, as if they were wholly replaced. Instead, several participants expressed a debt owed to people with disabilities in Uruguay based on the consequences of previous practices. The participants, particularly those from the government, embodied and integrated a disability rights paradigm beyond the scope of their role in place of their previous habitus, while remaining in the same structural position in an unchanged field.

Emotion according to Bourdieu, including the individual's experience of emotional upset in hysteresis, has been described as resting upon 'a durably installed felt sense of place... (which) reflects an intuitive grasp of one's position within the encompassing social environment' (Barrett 2018, p. 38). Thus, the emotional

experiences of individuals are rooted in a relationship between the internal state of habitus and the external conditions that surround them. In the case of the UNPRPD country project participants in Uruguay, the emotional tension and contradiction shared during interviews using such terms as feeling ‘lonely’ or ‘impotent’ to achieve ‘real change’ illustrate the experience of hysteresis. Most participants expressed contradictory views on the work, as seen in Table 1. Highs and lows demonstrate a new attitude towards the mission of disability rights, even though mismatched to an environment now perceived as stagnant.

Due to the disruption between the habitus and structure of participants, their habitus will remain unsettled until ‘a radical transformation of the social conditions’ (Barrett 2018; Bourdieu 2001, pp. 41–42). These participants, who have become agents of change, appear to remain in their new disability paradigm. As several participants observed, ‘I cannot unknow what I have learned’. The altered habitus equates to what Bourdieu saw as a durable change among decision makers in dominant social structures across Uruguay.

### Hysteresis and political change

While the UNPRPD altered the habitus of participating actors, Uruguay faced political changes during the November 2019 election. The hysteresis described above was further compounded by the risk of radical change in governance, destabilising the positions of power held by participants. Interview responses posed the question ‘If the most significant change occurred within individuals in positions of power, how much is internal change worth if those positions are replaced? In a tripartite approach with low capacity in civil society and threat to the stability of government, the project faced major barriers to structural change and transfer of responsibility from the UNCT as the project approached the end of its own timeline. The fundamental distribution of power leveraged by the programme changed when the remaining time and capacity (or for Bourdieu, capital) of individuals within institutions came to a close. This is especially true from a Bourdieusian perspective whereby a governing institution held power for 15 years, solidifying processes and procedure into a durable rhythm of practice that faced upcoming change. The system was no longer predictable and new norms would take their place; thus, larger field changes created a new layer of tension between individuals, social space and reactions to the project. With a more conservative government elected to meet the changing needs of the public (concerns such as safety in dense cities, according to participants), the uncertainty of project uptake with a new government inflated pressure to achieve radical change for Uruguayans with disabilities. For Bourdieu, embodying and legitimising change has a time component. Long-held exclusion is woven into the fabric of policy, practice, society and within the individuals that action the constructed norms. There was a sense of ‘running out of time’, or as PUN8 stated, ‘there (was) no political time’ to realise the newly integrated disability rights paradigm. Framed with Bourdieusian terms, the increased pressure to enact a new practice and reflect the disability rights paradigm was aggravated by field changes that further mismatch



**Table 1** Variation in participant reflections

Participant structure	Challenging reflections	Positive reflections
United Nations	Participant 8: 'This was the biggest opportunity to let people know disability is here in Uruguay, and we have not done that'	Participant 8: 'There was no dialogue between actors related to persons with disabilities' rights. So to change the life—the condition, the basic condition of life for persons with disabilities need a joint effort of government institution—not separately. Not each one in their own business. There is <i>one</i> business—the person of disability and their condition of life. They have to join their resources, their way of thinking of disability. And I think this project achieved this first step. A strategic step'
	Participant 16: 'If not for trainings and disability role in hospitals established... But I think otherwise it would be invisible'	Participant 16: 'Achieving the fact that this topic is going to be visible. Insist that it is on the agenda. It is not providing solutions, but it is establishing the problem on the agenda. We are looking for solutions, but it is difficult to make solutions with this fund. We say the money is to generate solutions, but the money is to establish the problem, in my opinion. We establish the problem, then build in the solutions. Since the results will always be partial'
Government	Participant 5: 'Regarding the other projects, we still don't have an output that is used in practice. We don't have anything in practice yet. The only thing I can think of, GBV, consultants gave information about how it is conducted at a national level. So we have done some work, but still a lot to be done. I agree with generating a space for all three to talk about these topics'	Participant 5: 'I think this project gave us an opportunity to unify our situation that disabled people were going through. This happens at different areas—health violence, but the heart is looking at the difficulties disabled people have in their everyday life. And the rights nondisabled people have that we don't even think about'
	Participant 3: 'Some of the products that we are undertaking now, two exploratory studies that should have been launched at the beginning—what is the worth of having them at the end of the project? I feel very lonely sometimes'	Participant 3: 'I dunno, we took a risk and in the process people who were more directly involved in the project learned that the most significant opinion is from the person with a disability. We can add on, we can put things in policy words, but the need—experience, is unique, is from persons with disabilities'
Civil society	Participant 7: 'Civil society maybe didn't answer as they were supposed to. They could not perform as asked—did not have capacity'	Participant 7: 'Because they are implementing, proposing and thinking about change. The projects fulfil the objective—maybe half we cannot complete, but generating change for sure. I'm convinced'

**Table 1** (continued)

Participant structure	Challenging reflections	Positive reflections
Consultants	Participant 2: 'Many Alianza organisations won't meet. Had meetings with DPO (OPD) organisations outside the Alianza. Alianza is not enough, but they were selected for this project. There <i>are DPOs</i> , just not in the project because of the agreements. And they did answer their calls'	Participant 1: 'They (training consultants) were expecting 65 people, all attended. In Montevideo, more than 100 people. I don't know if we can evaluate that with numbers, but we have the feeling that it was welcome by the audience'



participant's habitus with the practice contained in Uruguay's social field undergoing an ideological shift.

## Conclusion

Disability-inclusive development at a global scale is difficult to demonstrate with traditional programming, leaving much of the development process and outcomes unknown. Exclusion and inclusion express differently in diverse cultures and contexts, limiting any universal or fixed targets designed to monitor the effects of programming. In an effort to better understand human rights development in the context of disability, Pierre Bourdieu's theories capture abstract and concrete shifts in the underlying forces that perpetuate exclusion.

For some participants in this study, perceptions of the project's success became dependent on the upcoming elections. Participants had several concerns. Would the new government adopt the research and priorities generated by the project? How will new leadership adopt disability rights as a priority without the engagement and dialogue process facilitated by the UNPRPD? The UNPRPD project is a microcosm, a phenomenon. The aim is to transfer its processes and outcomes to local and mainstream structures in order to bring about wide-ranging social change. As of July 2019, the Uruguay UNCT did not plan to reapply for a second round of programming, concluding the project in March 2020. Is 2 years enough to create sustainable change, durable to withstand overlapping social changes such as a new government? Previous sections described the value of having inter-institutional engagement and bringing a unified approach to implement the CRPD—this is why dialogue is so crucial. But if the potential for a new government creates such high risk, how much is dialogue worth? If the projects rely on current conditions, how can projects be developed that are durable against unexpected social change?

Many participants embodied the ideals of the CRPD, recognising persons with disabilities as rights holders and experiencing discomfort at realising their new set of values were yet to be fully implemented across multiple levels of social life in Uruguay. The UNPRPD altered habitus in key project representatives, creating the sense of beginning an entirely new chapter as the project came to a close. Bourdieu's theory provided the context to underpin a broad range of participant reflections, diverse field dynamics and critical learning points for future disability-inclusive development projects.

## Limitations

Interviews were conducted during one month of the 2-year project timeline, nearing the end of implementation. Follow-up research may provide insights into changes made by the UNPRPD after the project is completed, particularly after the change in government.

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**Data availability** Manuscript contains data that will be available upon reasonable request.

## Declarations

**Conflict of interest** The authors have no conflicting or competing interests to declare.

**Ethical approval** This case study design and interview methods have been implemented in a previous post-graduate thesis study as well as the research presented, both having received ethical approval.

**Informed consent** Informed consent was provided in both English and Spanish, and all participants were offered interpreter services for effective communication. Accommodation for disability access was offered to ensure participation of all eligible stakeholders of the project. This publication has been approved by all co-authors.

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# 13

## THEORIES OF SOCIAL DOMINANCE IN GROUP- BASED HIERARCHIES

Reflections from the United Nations  
Partnership on the Rights of Persons  
with Disabilities (UNPRPD) project  
in Uruguay

*Holly Wescott*

This chapter brings together three related frames to contextualise the process of change within a project which aimed to promote the rights of people with disability. First, we briefly consider theoretical frames of social dominance and group-based hierarchies. Then census data from the country on which we focus – Uruguay – is presented to understand disability and demographics at the national level; to inform the ‘field’ targeted for change. We then describe the change project, which was a component of the larger United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). We explore the structural dynamics and changes that have taken place through the application of the UNPRPD in Uruguay. Finally, we review how our frames contribute to our understanding of the implementation of the UNPRPD in Uruguay.

The UNPRPD was established to create the sort of structural changes – that is, changes in social institutions – required to make realisation of the Convention (United Nations Convention on the Rights of Persons with Disability) (UNCRPD) possible. The UNPRPD works through a tripartite relationship between a number of collaborating United Nations agencies (minimum three), a government department or departments, and one or more civil society organisations (UNDP, 2016). Clarke (2016) notes, for implementation of a new law or regulation or, in this case, a Convention, “historical behaviours are required to change in line with the expectations underlying the regulation. . . . [O]ften, behaviours of more than one group need to change” (p. 32).

## Theoretical frames

Social dominance theory (SDT) (Sidanius et al., 1994) has gained much empirical support in the last two decades. It argues that there is an evolved human tendency to form and maintain group-based social hierarchies. These hierarchies may reflect any social designation, such as ethnicity, caste, class, or disability; where dominant social groups (e.g. those without disability) have disproportionate social advantages (e.g. high status or political power), and subordinate groups (e.g. those with a disability) experience disproportionate social disadvantages (e.g. poorer access to education, justice, or healthcare), even if their objective needs may be greater. SDT sees such social hierarchies as often “in large part created, preserved, and recreated by social institutions, or organizations” (Haley & Sidanius, 2005). Such social institutions “can powerfully promote or suppress existing social hierarchies based on how they allocate positive resources (e.g., prestige, wealth, healthcare) and/or negative resources (e.g., disdain, poverty, endangerment)” (p. 189).

Kurt Lewin (1890–1947) pioneered work relating to social change, including the concept of planned change, and provides an extensive range of valuable tools to understand and initiate change (Swanson & Creed, 2014). His basic theory of change posits a three-stage process: “unfreezing” of the current situation; “moving”, when the change actually takes place; and “refreezing”, when the new habit or norm is espoused or institutionalised (Bargal, 2014).

Lewin did not consider the importance of power relations, symbolism, different forms of capital, or the general idea that the privileged often prefer to maintain things as they “naturally” are (Lewin, 1939, 2013; MacLachlan et al., 2019). The work of Pierre Bourdieu does, however, address these issues. While his sociological scholarship was largely focused on social class, it has also been applied to the area of disability (Byrne, 2018; Wescott et al., 2021). This perspective is represented by Pret and Carter (2017) (Figure 13.1), which illustrates how the “field” is dominated by different forms of capital.

Extending Marx’s ideas of the importance of economic capital in shaping one’s position and opportunities, Bourdieu (1986) considered other types of capital too. For instance, cultural capital can be embodied (one’s accent), objectified (the type of car you have), or institutionalised (having a degree or title), all symbolising competence, authority, or status, allowing us to identify “people like us”. Bourdieu’s concept of habitus refers to individuals learning how to “play the game” that forms the repetitive behaviours of their social niche (Bourdieu, 1984), often seeing such a position as part of a “natural order”. For Bourdieu “the field” was where habitus was practiced and capital expended, with different rules applying in different fields: people with disabilities might have improved access to transport but not political office, for instance (Bourdieu, 1986; Bourdieu, 1990).

Sidanius and colleagues have demonstrated a range of ways and contexts in which people have a psychological propensity – they argue an evolutionary drive – to form group-based hierarchies, which imbue prejudicial attitudes.

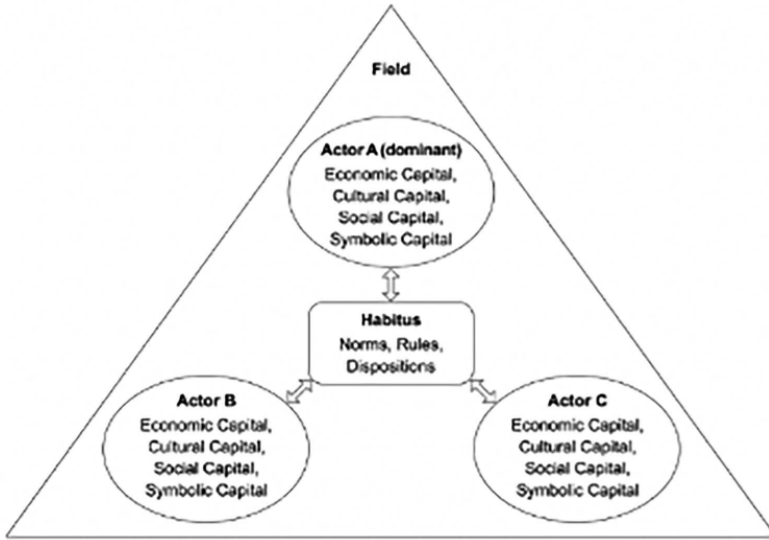


Figure 13.1 Illustration of capital forces in a field

Source: Adapted from Pret and Carter (2017)

Bourdieu recognises the social power dynamics of privilege and position, which groups often wish to protect: implicitly, if not always explicitly. Lewin's field theory has spawned the Theory of Change (ToC) movement, in which participatory methods are seen as central to being the change. This chapter therefore seeks to bring together theorising related to individual and institutional experiences of change (Breuer et al., 2016; MacLachlan & McVeight, 2021) through analysis of the implementation of the UNPRPD programme in Uruguay. Uruguay was a particularly compelling country to focus on because it is geographically interesting as a small South American country nested between much larger countries, was recently reclassified as a high-income country (The World Bank, 2019), is known for a progressive government, and is high on the development index (The World Bank, 2019). These conditions can serve as an interesting case study for a global programme designed to adapt to diverse development contexts, particularly as disability exclusion is not limited to countries traditionally found in development projects.

## UNPRPD country project in Uruguay

### Background

The United Nations is an intergovernmental organisation containing dedicated thematic agencies such as UNICEF focusing on children, WHO for health, and

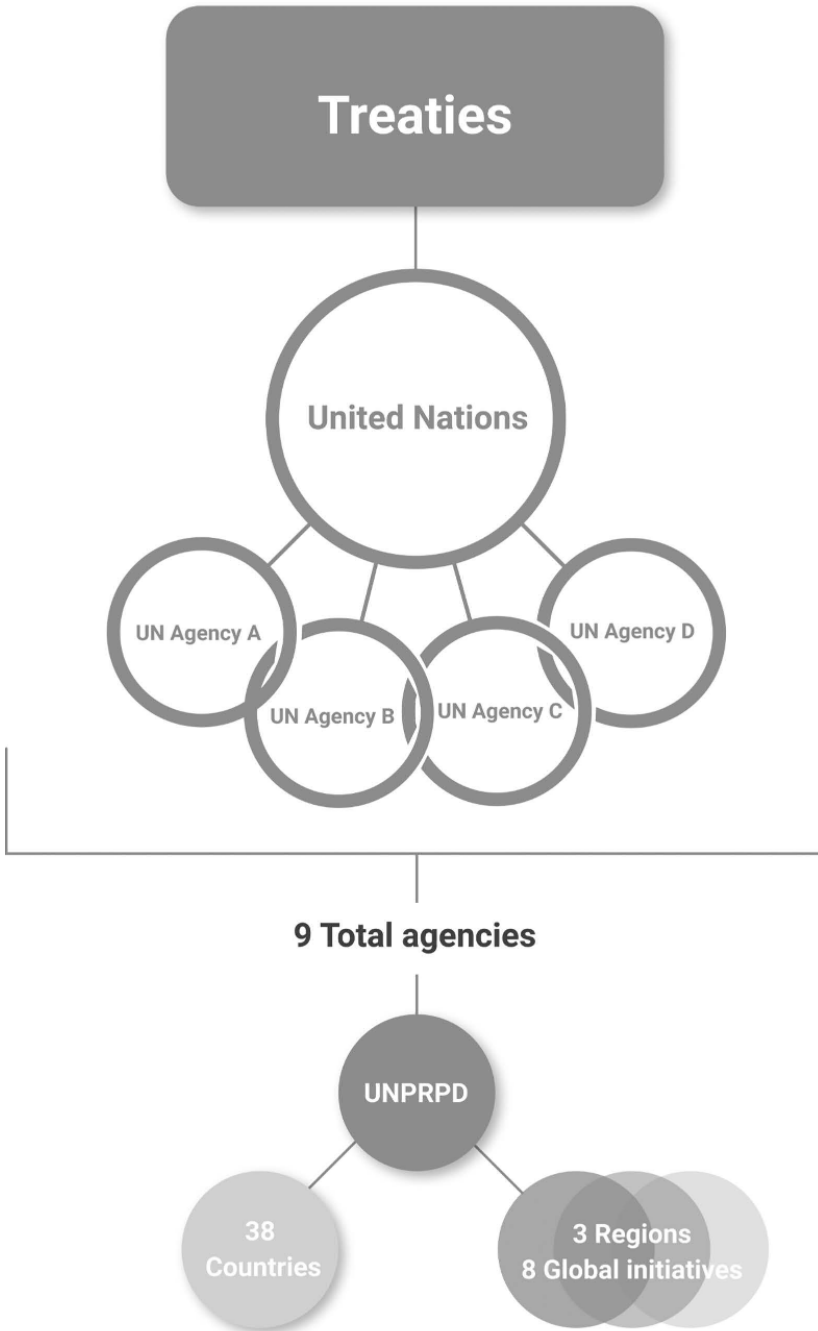


Figure 13.2 Conceptual diagram of the UNPRPD within the UN system

UN Women for gender equality within the larger UN system (United Nations, n.d.). Of the agencies and programmes within the UN system, nine participate in the interagency initiative called the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD). While there is no UN agency that focuses solely on disability inclusion, the UNPRPD promotes intersectoral participation from various sectors to mainstream disability rights as a component of directives within the existing bodies (United Nations, n.d.; UNDP, 2016). By 2019, when this work was undertaken, the UNPRPD had supported projects in 38 countries, three regions, and eight global initiatives around the world since its inception in 2011 (UNPRPD, 2019). One of these countries was Uruguay.

The United Nations system also supports the implementation of international treaties enacted for a range of populations such as Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Rights of Persons with Disabilities (CRPD), and more generally, the Universal Declaration of Human Rights. Each of these treaties outlines specific rights afforded to the individuals it serves to protect and is governed by UN committees to oversee government compliance through periodic reporting between governments, civil society, and United Nations country teams (UNCTs).

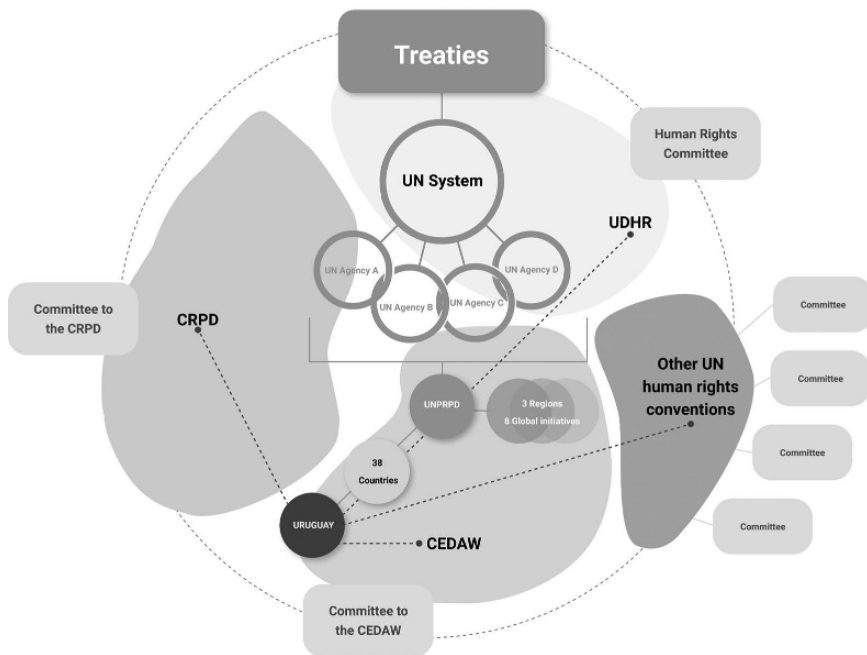


Figure 13.3 UN system field as it relates to the UNPRPD Uruguay country project



Table 13.1 Legend of acronyms

<i>Diagram term</i>	<i>Description</i>
CRPD	Convention on the Rights of Persons with Disabilities
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
UDHR	Universal Declaration of Human Rights

Uruguay adopted the CRPD on 3 April 2007, eventually ratifying it on 11 February 2009 (OHCHR, 2014). Uruguay, which is surrounded by upper-middle-income countries, has enjoyed sustained economic growth since 2003 (The World Bank, 2019) and a progressive government for 15 years, before the 2019 election (The Economist, 2019). In 2013, the World Bank reclassified Uruguay as a high-income country (2019). National poverty, extreme poverty, and inequality have remained low according to various measures (e.g. human development index, human opportunity index, economic freedom index) (The World Bank, 2019). Although political and economic stability have improved the living conditions of Uruguayans, and the CRPD was formally adopted, disability exclusion persists in the country as evidenced in the concluding observation reports from the Committee on the Rights of Persons with Disabilities (UNCRPD, 2016) and the Committee on the Elimination of Discrimination against Women (CEDAW) (UNCEDAW, 2016). The Uruguayan UNPRPD project sought to address this disparity by aligning the national frameworks previously enacted and the United Nations Conventions Committee recommendations.

In response to the committee recommendations, the United Nations Office of the Resident Coordinator applied for project funding to the UNPRPD programme to initiate a multi-partner project. The proposal was accepted in 2018 for a one-time project cycle of 24 months, concluding March 2020.

The UNPRPD project comprised three pillars of work: 1) to advance universal access to health through sexual and reproductive health rights of young persons with disability, 2) the prevention and response to gender-based violence (GBV) among persons with disability, and 3) improving the systematised collection and use of disability data. Each of these pillars held working group meetings with representatives of each stakeholder group, followed by a monthly plenary session with all key actors for ongoing project discussions. Some actors who were involved in multiple pillars attended more than one thematic meeting. For example, the Ministry of Public Health assigned one representative as liaison to the UNPRPD on behalf of the institution, who engaged with all three pillars for the project duration.

## Methods

This study initially followed a traditional qualitative case study approach with 22 semi-structured interviews among United Nations, government, civil society, and consultancy representatives of the UNPRPD project in Uruguay in 2019. Data was collected using the most significant change technique (MSCT) (Davies & Dart, 2005; Quilliam & Wilson, 2011), a semi-structured appreciative enquiry method. Open-ended questions were designed to prompt reflection while maintaining the scope of distinct responses within the UNPRPD project. Following the data collection, interviews were analysed using interpretive phenomenological analysis (IPA) to better understand how the key UNPRPD focal points make sense of the project goals and implementation process (Smith et al., 2009).

During the site visit during which interviews were conducted, several participants wondered out loud, ‘We know disabled people are excluded, but to *where?* *Where* are they?’ This question lingered as the project sought the participation of persons with disabilities, aiming to amplify those voices above all else. Engagement was challenging for many reasons discussed in depth later in the chapter; however, it led the researchers on a quest to better understand the tension of local disability exclusion and efforts to increase participation.

The UNPRPD project proposal noted the 2011 census results citing that 16% of Uruguayans have some form of disability (Ines Núñez, 2014), providing a quantitative data set to explore the concerns expressed by project participants. GIS software and statistical analysis revealed noteworthy demographic distributions that bring light to the question project participants continued to ask themselves in search of persons with disabilities: ‘*Where* are they?’

Demographics were only part of the story. While the UNPRPD global programme provides guidance for project development, there are contextual forces unique to each country that are difficult to anticipate in full before decisions have to be made. Activities must be determined and partnerships engaged very early on when implementing a two-year fixed timeline, revealing many key insights only later upon reflection.

The MSCT questions are designed to engage participants in reflection on their experience and connect the events of a story with the *how* and *why* it illustrates something significant. The questionnaire is designed as an appreciative inquiry, engaging key focal points in exploring the positive events generated by their work to better understand what promotes successful implementation of disability rights in structural development. Responses were unexpected as participants were not able or willing to provide a story illustrating the ‘most significant change’ since the project began and instead shared concerns. The MSCT still provided tools to reflect on their concerns. For example, the following questions ask the participant to think about how that concern came to happen. In other words, the questions prompted a retrospective field analysis of processes in specific terms (e.g. contextual factors, power differences). These responses provided the data to code inductively as the results were unexpected and fit no predetermined framework.

A case study is used to understand different perspectives of a shared phenomenon and removes the guise of a neutral researcher. Measures are taken to reduce bias and overinterpretation through systematic data handling. IPA looks at the full scope of a phenomenon by incorporating the diverse participant perspectives of a shared experience first by reading all transcripts in full for clear understanding, then coding interviews for themes, connecting the themes as they relate to each other, and repeating the same protocol with all interview transcripts in the same fashion before proceeding with the analysis (Smith et al., 2009). Interpretation of participant responses takes place at only two points in the data-handling process: identifying themes and conducting the written analysis. The emergent themes often use the terms given by participants as seen in the illustrative quotations; however, the interpretive synthesis of the collective responses provides the meaning derived from the study. IPA identified the following themes; these will be discussed in turn.

### *Participants*

Each UNPRPD project partners with UN agencies, government ministries, and civil society organisations relevant to the priorities set for implementation. Some projects have several ministries involved and one national disability organisation (or vice versa), varying the distribution of partners in each stakeholder group. For the purposes of this case study, gathering interview data from each of the three main stakeholder groups was essential to capture data

*Table 13.2* IPA superordinate and subordinate themes

<i>Superordinate themes</i>	<i>Subordinate themes</i>
<b>Programmatic barriers</b>	Managing participation <ul style="list-style-type: none"> <li>• Project coordinator</li> <li>• Civil society engagement</li> <li>• Representation</li> </ul> Hierarchical positionality <ul style="list-style-type: none"> <li>• Theory over action</li> <li>• Determining capacity</li> <li>• Individual representation</li> </ul> Capital capacity
<b>External forces</b>	Field changes <ul style="list-style-type: none"> <li>• Status implications</li> </ul> Theories of change
<b>Internal forces</b>	Awareness <ul style="list-style-type: none"> <li>• Paradigm shift</li> <li>• Increasing structural stability</li> <li>• Building partnerships</li> </ul>

across hierarchies that interact in multiparter projects. The distribution of focal points per stakeholder group varied in each country; thus, some groups offered fewer individuals to select from for interviewing. Despite the variation in focal points per stakeholder group, all three institutions (UN, government, and civil society) were represented in the interview data for this study. Representatives from 12 major institutions participated. The National Institute for Women in the Ministry of Social Development (Inmujeres) was the only major institution involved in the project from which the researcher (HW) was unable to secure an interview; nonetheless, coverage of all other partners provided broad perspectives surrounding the UNPRPD Uruguay project.

### *The United Nations*

Six representatives from UNFPA, UN Women, WHO, the Office of the Resident Coordinator, and the UNPRPD project coordinator participated in interviews for this study. These representatives take part in several United Nations projects in addition to the UNPRPD (with the exception of the UNPRPD project coordinator) and act as focal points for the UNPRPD with their respective agencies.

### *Civil society*

Member states and UNPRPD projects commit to the CRPD in pursuit of realising the rights outlined across all 50 Convention articles. One key piece of the Convention (United Nations, 2006) is Article 4.3, stating

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

In practice, Article 4 mandates direct participation with populations of persons with disabilities, either individuals or their representative organisations, in disability development efforts.

The primary partnership for civil society representation is the Uruguayan Alliance of the Organization for the Rights of Persons with Disability (also referred to as *Alianza*, or the *Alliance*). Established in 2016 to produce a shadow report to the Committee on the Rights of Persons with Disabilities, the Alliance is an umbrella organisation of various disability and service-specific civil society groups. Initially, the *Alianza* comprised 6 member organisations located in the capital, Montevideo, but it has grown to roughly 27 organisations with recent expansion to the interior of the country. The umbrella group's membership varies as organisations enter and exit the Alliance. As of July 2019, the *Alianza* was a civil society umbrella organisation with no OPD membership.

The Alianza was asked to join the project during the initial planning and recruitment phase based on their participation in the Convention reporting system and UNPRPD programmatic criteria for representing a broad range of disabilities. According to participant reports, other well-established OPDs or disability organisations align with the longstanding medical model of disability, making the Alliance a natural fit for the UNPRPD's rights-based programme.

Participation in the Alliance is on a volunteer basis, with the exception of grants and hired consultancy. The organisation has no funding stream or central body for coordination. Service providers or parents of persons with disabilities head the various member organisations, conducting most of the Alliance's work outside business hours without compensation. The project hired a consultant to support participation from the Alianza, attend meetings on their behalf, assist in coordinating the variety of organisations, and help develop an operational structure that would grow and continue beyond the scope of the project.

### *Government*

Several government institutions were invited to participate in the project, including the Administration of Health Public Services (ASSE), Uruguayan Agency for International Cooperation (AUCI), Social Provision Service (BPS), Ministry of Social Development (including the national disability program PRONADIS and National Institute for Women, Inmujeres – MIDAS), the National Statistical Institute (INE), and the Ministry of Public Health (MSP). A focal point from each institution was selected to represent their department within the UNPRPD project and channel expertise to and from the project.

## **Results**

### *Census data*

The metaphor of fractal geography suggests that wherever, in whatever space you look for disabled people, study us as a social group, as a community, you should cast your eye on the outer fringes, regardless whether that space of inquiry is Manhattan, rural Japan, the industrial zones of Sao Paulo, or the shanty-towns of Lagos. I am not saying that all peripheral space is the same. . . . What I am suggesting is that wherever we [disabled people] are located, we are on the outside looking in.

*(Charlton, 2010, p. 197)*

Located in South America between Brazil and Argentina, Uruguay declared its independence in 1825. The total population of Uruguay is 3.449 million (The World Bank, 2019). Of these, roughly 1.3 million residents live in the capital, Montevideo (Ines Núñez, 2014). While the capital is a small region of the country, it is a highly populated urban area based on the 2011 census.

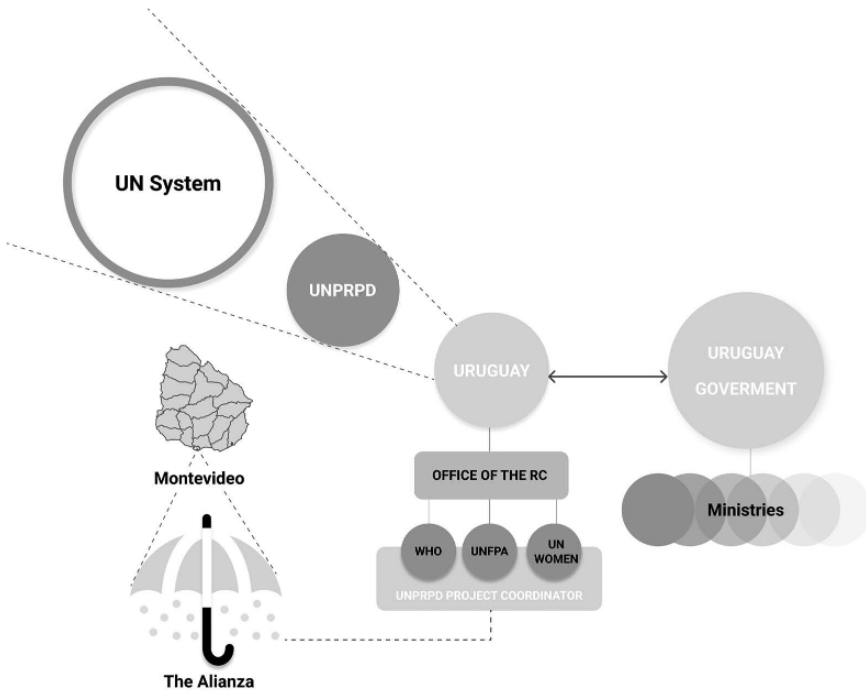


Figure 13.4 UNPRPD Uruguay country project-partnering entities

Table 13.3 Legend of acronyms

Diagram term	Description
UNPRPD	United Nations Partnership on the Rights of Persons with Disabilities
Office of the RC	Office of the Resident Coordinator
WHO	World Health Organisation
UNFPA	United Nations Population Fund
Ministries	Represents seven participating Uruguayan government ministries
The Alianza	Participating civil society organisation

Disability data was also collected in the census of 2011. A survey called the Washington Group Questions were developed as a set of general disability measures to standardise and compare disability data internationally (Madans et al., 2004). Since implementing the use of the Washington Group Questions on the 2011 national census, 16% of Uruguayans have reported having

a disability (Ines Núñez, 2014). Of this 16%, 60% were women, reporting higher absolute percentages across all categories of mild, moderate, and severe disability (Ines Núñez, 2014). Although the interior of the country is much less densely populated than the urban areas, the 2011 Uruguayan census reports a disproportionate amount of disability in rural municipalities. While the raw number of Uruguayan persons with disabilities residing in the country's urban areas is high, the proportion of disability is significantly lower in the cities and significantly higher in some of the most rural regions of the country. The three municipalities with the highest ratio of disability to population are clustered on the east side of the area that borders Brazil and have relatively low populations (Ines Núñez, 2014), as shown by the "hotspot" analysis (Anselin, 1995) in Figure 13.5. Many disability-related resources and services are centred in the capital, Montevideo, where proportionally few persons with disabilities reside, including the engagement for the UNPRPD project. In contrast, the municipalities with the highest proportion of persons with disabilities are, as Charlton describes, on the periphery.

### Interview data

The Uruguayan case study affirms the abstract and lived implications of the group stratification he described. The census data in 2011 uncovered disability 'hotspots' and 'cold spots' whereby persons with disabilities live on the fringes



Figure 13.5 'Hotspot' analysis of Uruguayan municipalities

of social action far outside the capital, Montevideo. The literal manifestation of persons with disability on the periphery was mirrored by the lack of meaningful participation reported by the interview participants in the UNPRPD project. The challenge for initiatives such as the UNPRPD is not how to recognise differentials in power, position, and privilege, which have historically marginalised people with disability, but to prevent these from dominating the process of change which seeks to empower marginalised groups. We now consider this by reviewing our results in relation to the key theoretical frame introduced at the beginning of this chapter: 1) group-level behaviour is rooted in historical hierarchical positions in a multistakeholder initiative such as the UNPRPD, 2) different forms of capital operate within and between groups that can facilitate or hinder efforts towards implementing change, and 3) theories of change are rooted in contextual forces that must be embraced to implement targeted outcomes.

### Programmatic barriers

#### *Managing participation*

The UNPRPD project in Uruguay was proposed by the Office of the Resident Coordinator and implemented by three UN agencies: UNFPA, WHO, and UN Women. The project team assigned a focal point for each agency, or a point of contact for meetings, technical support, and operations. Noting the complexity of multiple UN agencies, multiple government ministries, and an umbrella civil society organisation (discussed in more detail later in this chapter), the UNPRPD country project allocated funds for a project coordinator from within the UN. The coordinator's residence was designed to be split evenly across the three agencies to promote neutrality (autonomous from any one UN agency) and facilitate implementation across the partnerships.

#### *Project coordinator*

The role of the coordinator was valuable to many participants. For example, one government participant shared,

[Without a coordinator] [t]hat would replicate the exact same thing that is happening now. Talking about disability in isolated sectors. What we want is that disability is talked about everywhere, because the life of disability is everywhere, so they need to come together. This work is demanding for all actors, but they have quite an overall vision.

The UNPRPD programme does not allow for a project coordinator, according to the UNCT. Despite this regulation, a project coordinator was appointed as



a ‘technical assistant’ to work around the UNPRPD global programme design. A UNCT representative shared:

One of the conditions of the proposal . . . you are not authorized to have a project coordinator. It is impossible to have a project coordinator in the budget. So we have to [them] as technical assistance. All the countries did the same, I can imagine. It was impossible to have 30 different agencies in one room without some coordination. [The coordinator] was hired after the development of the project. There is no way – it doesn’t make sense to not have a project coordinator. [There are] a lot of joint projects where you can apply for some money, but they put in some conditions that are ridiculous. For this project, the time was very short. If this is a new agenda in the country – it is impossible in some months to do something. This is not an issue that is much more mature in the country – this is a new topic. And they don’t allow a project coordinator like that. So we camouflaged that.

While the UN recognised the necessity of project coordination and was able to modify procedure appropriately, civil society engagement was similarly selected by *technical* capacity, which resulted in those organisations most represented by persons with disabilities being least likely to participate.

#### *Civil society engagement*

One of the primary challenges to the project was a lack engagement with persons with disabilities. According to several research participants, the UNPRPD programme requires an umbrella or national disability organisation for the purpose of including diverse and state-wide representation. Unfortunately, this became a barrier to entry for local representation. A participant from the government explained, ‘[It is] not that there are no OPDs – just not in the Alianza, and not in an umbrella or national configuration’. In the case of Uruguay, a national DPO was not operational (see Participants). The Alianza was selected in response to the shadow report issued in 2016 for the Committee to the CRPD, having gained previous experience interacting with disability rights through an international framework. Technical expertise in developing a shadow report and previous engagement with the UN system were not UNPRPD programmatic requirements; however, it became the criteria for participation, despite the lack of disability membership. According to many project representatives, the Alliance had two capacity issues: 1) Alianza is not an OPD, and 2) Alianza functioned as a group of individual organisations without a central body.

#### *Representation*

Reflections on the absence of disability representation was the most common overall theme across all interviews. One government participant shared: ‘The

Alliance was born in controversies – some OPDs don't recognize the Alliance as a legitimate organisation of representation – by the time I joined, the Alliance was already signed in.' Another participant from the UNCT perspective shared,

The issue is there is no person with a disability. The voice is from their parent. They are very involved family, but there is no people with disability. There is always something that is in the middle – people who are in the middle – the family, the social leader. Their voices have to be here, have to be expressed. . . . The project was organized to help them be the main actors.

Some participants felt most Uruguayan disability organisations were led by parents or providers, whereas others recognised the availability of local OPDs that were not formally enlisted in the project due to being single-disability issue organisations. Some participants sought opportunities to gather the expertise of persons with disabilities for input where the Alliance was unable to support the ongoing activities. A project consultant shared,

Many Alianza organisations won't meet. [We] had meetings with OPDs outside the Alianza. Alianza is not enough, but they were selected for this project. There *are* DPOs, just not in the project because of the agreements. And they [outside OPDs] did answer their calls.

Another participant explained, '[There are] about 600 organizations focusing on disability, including DPOs (OPDs), only 28 are in Alianza – mostly family representation. No other major federation – no other intuitive place to go'. The Alliance was the only group to meet the programmatic need for an organisation serving a range of disabilities, but it did not bridge the project closer to persons with disabilities. Mitigating the local hierarchy between decision-makers and rights holders was an ongoing effort by the UNCT, made more difficult by the regional distribution of persons with disabilities and the umbrella organisation requirement.

The absence of coordination to unify the roughly 27 separate organisations was a challenge in the face of providing a structural proxy for Uruguayans with disabilities. The Alliance membership was made of working professionals advocating for disability rights during their off hours or parents of individuals with disabilities of all ages who had to divide their time between professional, family, and advocacy obligations. One UNCT participant asserted,

I cannot blame them. They are full of everyday challenges. Everyday obstacles. Everyday needs. But they are losing the strategic opportunity that is this project. It is not a question of blaming them. It is a question of talking with them and help them to realise what this means for Uruguay and for the life of persons with disabilities. It is the first project, and it will be the last one.

### *Hierarchical positionality*

Sidanius's work on SDT explores the evolutionary tendency to group and situate into hierarchies. Further, these groups may operationalise dominance in different ways depending on the institutional socialisation. The UNCT serves a central role by bringing the UN system to local settings and are the technical expertise offered by the UN to country governments. There remains a hierarchy within the UN system whereby the UNCT operates within the larger UNPRPD inter-agency programme, nested within the larger UN framework. Thus, the UNCT implements the UNPRPD programmatic rules by way of UN institutional approaches. While the UNCT in Uruguay was tasked with framing the project around the overarching UNPRPD programmatic operational framework, they also determined which rules to break. One of the issues exerting influence on the project was the need for disability representation in their tripartite partnership. The programmatic requirement for an umbrella or representative national organisation was identified by focal points as a major barrier in Uruguay to realising the thematic objectives in a meaningful way. Several respondents noted being aware of the mismatch but lacked an alternative organisation that met the required criteria. While this rule was upheld despite the impact on the project, the UNCT found a way to hire a coordinator under a different title. This coordinator role is known as such and found in other country projects, recognising some rules are openly negotiated while others were upheld.

Unlike some of Sidanius's work around in-group solidarity, there is little evidence of participants trying to protect their group status; rather, UNCT representatives were forthright in their responses. The data showed active recognition of the missing voice of persons with disabilities as an impediment to implementing 'real change'. Many of the respondents made efforts to include persons with disabilities via consultancies or informal engagement yet often thought out loud, 'Where are they?', wishing to minimise the distance between groups rather than preserve it.

### *Project priorities*

Significant effort went into cultivating the partnerships after the focal points were selected; however some key decisions were determined by UN capacity during the project proposal phase prior to engagement.

In practice, requests for project proposals are sent internally to the United Nations and submitted by UNCTs. Projects originate from the United Nations, rather than civil society or government, and then the UNCT proceeds with the partnership approach outlined in the UNPRPD programmatic framework. One government participant who joined the project after the proposal was approved for funding reflected,

I asked myself, '[W]hy were these components chosen over the many issues that are pending or are a priority on the disability rights agenda

in Uruguay?’ [It has] more to do with the UN agencies’ willingness and capacity for the project. Started with UN and their ‘capacity and willingness’, *then* a dialogue with the government. The government said they were involved and chose the priorities together. It really doesn’t add up to me.

Another statement from civil society revealed this sentiment:

I haven’t had the opportunity to explain this. They already have the agenda decided. Sometimes I can give my opinion, but many of them are interested in the Alliance . . . but I am not very appointed sometimes, because I am not formally appointed. But I always attend because you have to listen to everybody.

While consensus and dialogue were fundamental tools in the project, this aspect was reported to be true only after priorities were chosen based on the availability of the UN. Additionally, there were perceived differences between official and unofficial appointments to the project. The previous participant quote was from a member organisation of the Alianza, though neither was, or felt like, a formal focal point with decision-making authority.

### *Theory over action*

One area of focus came up several times – the desire to have included rehabilitation in the project. This was particularly true as focal points from the Ministry of Health recognised the collaboration with WHO and UNFPA. Rehabilitation felt like a more pressing need than GBV and involved the same institutions engaged in the project. A government representative had a practical consideration, stating,

The project in the UN has helped with the sexual and reproductive health [and] concepts for diagnostic training, but it doesn’t cover the more specific aspects of rehabilitation in the Ministry of Public Health . . . We made theoretical progress without having real things to offer [such as] rehab in health. [We] can have all the theory, but it is not only about the technical support.

The UNCT considered the need for rehabilitation in disability development for Uruguay; however the project sought a different direction, explaining,

Rehab is not involved in this project. . . . [W]e strongly defined that rehabilitation will not be included in the project because it is strongly based on the medical model. This main objective of this project is to promote the social model of disability.

The UNCT wanted to emphasise the need to change social structures, rather than intervene at the individual level. As a result, the option to address rehabilitation was not prioritised for the project.

### *Determining capacity*

The UNCT was aware that priorities were selected for the project based in part on capacity, stating, ‘This project could have been very different if it were focused on education with UNICEF, or labour and ILO, but the results of the capacity to advance were these 3 agencies.’ The same participant wrestled with the process, sharing, ‘[We] had to make critical choices – for example, not to include education – that is a very critical issue. But we had to choose.’ Capacity of the United Nations was the first line of decision-making to ensure the project had support within the UNCT. The thematic decisions were felt throughout the project by many participants; however, civil society engagement was widely considered the primary barrier to the overall strength of the project.

The perception of civil society’s capacity was rooted in the absence of direct representation and familiarity with UN systems to interact on project terms. Some issues led to disheartening experiences for project actors. One participant candidly shared their unmet expectations regarding the Alianza: ‘At first, [the project sought] more representation to make decisions, now they are trying just to make it work.’ Partnership with the Alliance came with barriers to engaging some additional OPDs, as well as inter-organisational competition, as described by one participant, who said:

[We] wanted to give civil society some independence to come up with their own activities: [a significant amount of funding] to civil society to create workshops on gender-based violence, and they have only reached six women with disabilities. Some organisations left Alianza because for funds – set off conflict in the Alliance regarding who would receive the funds and why – the grants weakened the Alliance.

The Alliance runs on a volunteer basis; thus, they were given funds to support two organisations. They recognised the difference in stakeholder resources and aimed to reduce barriers and increase engagement in the project. Introducing a small amount of economic capital to an environment without a financial structure made fair distribution difficult and resulted in internal conflict with small-scale results.

The perspectives from within the Alianza (including consultancy) were much more optimistic about the growth of the Alliance, having expanded organisational membership from being limited to Montevideo to adding a few groups from the interior of the country – increasing their capacity. Representatives from the Alliance attributed their progress to the UNPRPD support. For example, one interviewee said,

The [UNPRPD] project allowed the Alianza to organise its work. And make it possible to show its work with a wider audience (because we are the) only organisation representing disabled people recognised by the state. The Alianza is too young, just started in 2016.

Despite the growth of the Alliance, participants outside civil society felt the challenges were still too significant to engage in the project as planned. One participant reported, 'We feel impotent, trying to find the real mechanism to give them a voice and protect and empower them. It's hard.' Most notably, in an interview with a Spanish-English interpreter in the session, one participant spoke directly in English to the researcher, saying, 'It's not working. The Alianza is not working.' While participants acknowledged what was feasible for each of the stakeholders to deliver, the ghosts of what could have been lingered in conversation through statements such as: 'It is a bit sad we are not embedding that participation into the project. It was a unique single opportunity', and 'I think we lost in quality . . . on what could have been'.

### *Individual representation*

The project did have key individuals with disabilities assisting in various roles that proved to be very powerful in the interviews with participants. When reflecting on the capacity limitations of the Alliance, many recalled the impact that individuals with disabilities had when invited to the inception phase or during training sessions. The initial intent of having a representative organisation was to avoid narrowing a diverse population of people into a few consultants or other individuals. This possibility was a known risk to participants. They continued to encourage engagement from the Alianza while several select individuals with disabilities brought the power and representation that many participants sought. One response noted,

[T]here is an incorporation of a disabled person in the team of teachers. Very independent woman, and she has been fighting for the rights of disabled people, and that is a strength when you think about reaching people with a message. Especially for health teams.

This impact was particularly true of the inception phase that publicly launched the project to stakeholders in Uruguay. Several participants reflected on this event as a major success for the project. One government participant stated,

It is so very few times that persons with disabilities were heard, and have the chance to speak to government officials, to public, policy makers, and we created an environment. That was something that we – that gave these people the chance to think or be confronted with exclusion or with a different image. One girl was talking about all her achievements, and that helped break barriers of the vision of disability that is current. Charity

and that. But I think that moment was very moving. . . . It was a big ceremony, and everyone was listening. So it was worth the risk. That doesn't change the life of anybody, but that was something. It was important.

The UNPRPD designed projects to include persons with disabilities in all stages of work. Special events such as the inception created the opportunity to reach outside an official partnership to highlight the strengths of representation from persons with disabilities. Those individuals were fewer than the team aimed to engage and solidify as partners, yet they played a significant role in guiding the vision for the project.

### *Capital capacity*

Bourdieu's habitus describes the modification of historical behaviour practiced by individuals as a feedback loop for change between agent (historical behaviours) and state (laws or regulations). This begins to give shape to enacting change. Based on Bourdieu's work on embodiment and structural behaviour, programming should recognise the role of capital in the different positions and influence of partners engaged in the project. Further, Lewin outlines a five-step force field analysis to manage change at the group level by defining the desired change and mapping strategies to create a path forward, and while the UNPRPD did not explicitly use or cite in their process, they followed a similar approach. The Uruguayan case study seen through Lewin's work highlights a key force missing from his framework that Bourdieu examines in depth. For example, Lewin's field analysis begins by defining the problem space, which is highly dependent on who is doing the defining. Each step that follows would vary greatly based on which persons are conducting the analysis. For Bourdieu, the capital underpinning the power distribution in a hierarchy is essential to a field and was a major point of tension in the UNPRPD Uruguay project.

Forms of capital were evident in the participant responses with some awareness of their implications. For example, the UNCT recognised a volunteer organisation's limited capacity without a governing body or funding stream. Importantly, both the UNCT and government focal points recognised the impact of symbolic and cultural capital and the inability to replace the engagement of persons with disabilities or a representative OPD with civil society that does not possess disability membership. These were meaningful barriers to change in the project. While participants were aware of these issues, there were fewer comments on the relational aspect whereby capital is relative. As a result, an absence of power in some areas has a relationship to dominance in others. Many participants reported feeling limited by decisions that had been made early on in the project, such as thematic priorities, even if the decisions came from within. More dominant structures exerted small amounts of authority in contracting individuals with disabilities in any role possible but did not alter the internal procedures that led to those barriers when applied to the Uruguayan context. Likewise, government focal points agreed the priorities of

the project did not reflect more urgent local needs but felt the opportunity to pivot was outside their authority. So, while some forms of capital in partnering structures were recognised, a structure's own power and dominance to make changes were not felt when encountering roadblocks.

## External forces

### *Field changes*

Structures have relational implications that demonstrate the hierarchical dynamics in disability development projects, such as UNPRPD regulations for an umbrella or national OPDs mismatched with the availability of such a structure in the country. These hierarchies operate in country contexts that also respond to social dynamics. Two of the changes in social space that were seen as impactful to the project were the reclassification of Uruguay to a high-income country in 2013 and the change of government in 2019. Both these external conditions began to define the participants' perception of project success. Participants could acknowledge positive outcomes from the project, but the successes were shadowed by the social changes underpinning their work. For example, a member of the UNCT said,

I believe the two or three studies we have produced from this project are really an advance to measure and assess disability. The access to social benefit. The guide on sexual & reproductive health. I think they are very good. They have a strong quality. And so based in scientific information, so I feel they are a smart contribution. It is a very valuable output, but the government have no real time to implement them.

The elections were seen as a deadline to secure the project changes, knowing the government would likely be replaced by a more conservative body. The same UNCT representative described a dual project timeline – one for the UNPRPD and one for the period of government:

The different groups may propose, and they – each official or group may propose some changes, but there is no time to produce those changes. That is a fact. There is no time to propose to the Parliament, to the government, to produce those changes. But it will remain updated and documented for promoting the changes in the future – in the short future, in the near future. Now there is no political time.

Prior to the elections that November, which did result in a change of political party, participants felt the likelihood of change was a direct concern for the project. One government participant worried, '[There is a] real risk all the hard work they have done stays in a limbo. Risk of having to do it all over again'. Another from the UNCT shared, 'I don't know how the future will be when the



project finishes. Because there are these elections. But certainly political change. That may be a threat for the project'. While the team was trying to 'make it work' with civil society, the looming political climate made the project feel increasingly dependent on external factors to achieve substantial change for persons with disabilities in Uruguay.

### *Status implications*

Additional pressure from the country classification to high-income status made the UNPRPD project feel like the last opportunity Uruguay would receive of that magnitude. One participant explained,

It is not a competition. In a country like Uruguay, the agencies have to justify the reason they are here, there is a pressure – or syndrome of the winner – is a little bit present. They are cooperating pretty well, but I mean, that is present.

The need to prove the value of the work as funded projects become redirected to low- and middle-income countries leaves little room for error in a tight, two-year timeline. One participant from the UNCT shared, 'This was the biggest opportunity to let people know disability is here in Uruguay, and we have not done that'. Another explained the urgency for increasing the capacity of civil society before the end of what felt to some like their final opportunity: 'That is why it is important to strengthen the Alliance. The project will end and the Alliance will end'. Participants spoke with finality in their responses over the changes happening around them, many of which were not the changes they imagined going into the project.

### *Theories of change*

Reflecting on Lewin's field analysis, the case in Uruguay surfaces the question: what if some restraining forces are self-imposed by varying structures within a hierarchy – particularly those structures with the most resources to exert force? Bourdieu's concepts of multiple, overlapping fields expand the scope of analysis to include hierarchical power such as locating the authority to choose how mismatched rules are handled and the implications of structural authority. There were several layers of analysis to consider in addition to the scope of work aiming to take something created by the project and alter the external environment or their ToC. The project had a traditional, outward ToC whereby a tripartite partnership would collaborate to improve sexual and reproductive health, gender-based violence, and systematised disability assessments. There was a larger programmatic framework to follow, which, on occasion, created barriers to what participants called 'real change'. The programmatic framework, operations, and authority within each stakeholder group, the demographic distribution of persons with disabilities in the country, local needs,

and preexisting capacity were all under analysis; however, the analyses did not come with an internal (reflexive) ToC. Neither the UNPRPD project nor any partnering stakeholder was intentionally perpetuating the peripheral role of persons with disabilities; rather, the tripartite partnership reflected the preexisting social hierarchies. The participants did not report an established action plan for what to do if the broader UNPRPD framework created barriers – a ToC for their own internal process.

Finally, the participants expressed an urgent need to ‘refreeze’ the changes made by the project before elections would change government power. Bourdieu’s field theory is helpful to visualise forces coming from multiple directions with varying degrees of importance. There are limitations to what the biggest actor in a system can do when another field force encompasses the project. Meaning that even with all the power of the UNCT and participating government focal points, if the Uruguayan public voted for a new party that destabilized the project’s work, there was little control the project could exert to push their desired outcomes forward. The project was hosted within the Uruguayan context, and that context could suddenly shift in a different direction than the project was designed to operate within. Ultimately, the participants reported concern over the longevity of project outcomes as a new government took office, and the project approached the end of its funding.

## Internal forces

### *Awareness*

The external forces shaping the project were significant to the participants in this study. That being said, there were several positive changes within the project, particularly the individual changes that extended into their structural role. Beginning with an example of individual change, a UNCT participant described the growth in their personal awareness stating,

As a personal experience, I learned a lot about persons with disabilities and how to act when you are [with them]. . . . all my instinctive actions are not always right. With blind people, I have to talk and not just act. That has increased my capability to have relations with persons with disabilities.

These actions were not limited to the internal process. One other UNCT participant was compelled to order new business cards with Braille embossed onto the material. She shared, ‘You are called to action, you are touched by it. . . . [T]hat is the way this project touched me, I changed some part of my life – my (business) cards. This is the personal change I have made.’ She continued to

describe how the disability rights paradigm from the project changed her approach to work within the UNCT:

For the first time, I had to be very sincere. For the first time, we at the office rethink the issues that [come up at] our public events: for example, if they were accessible for everyone. . . . But for me, it was a project that made me ask me questions about what we are doing every day from [the UN agency].

### *Paradigm shift*

Internal changes were found in all three partnering structures according to interview reflections. A UNCT participant reflected on a shift in government dynamics toward fostering future progress as a result of the UNPRPD:

It is not easy that actors convince themselves to take steps that can really change their structure. Those steps we are talking about from the economic point of view, the human resources, to the vision also. The institution is questioning itself and admitting that something that it has been doing for a long time, they are not doing the right way. There can be a better way to do it. I think this – taking this awareness is a super big step. It's the key to be open to the change. If you don't do this step, all the changes you can achieve are just temporary.

A representative from a government ministry shared a similar sentiment, stating, 'We are coordinating about real things instead of talking about what we don't have. That is new and a change'. Structures previously unfamiliar with disability rights became more open and willing to change from within to become more inclusive and move priorities forward.

### *Increasing structural stability*

The Alianza also noticed internal changes as a result of the UNPRPD project. For example, one participant on behalf of civil society noticed,

One very positive point, thanks to the project and thanks to the activities, the Alianza could go into the interior of the country. Lack of funds, so it couldn't do that before. Used to be only concentrated in Montevideo – now met very receptive groups to join Alianza.

Crucially, a member of civil society reported increased engagement with persons with disabilities: 'Participating in the project allowed the Alianza to include activities to the disabled, and include disabled people in activities, and

reflect the needs of disabled people'. While the capacity of the Alliance presented challenges for this project, it did work towards deepening the role of persons with disabilities in the existing umbrella organisation.

### *Building partnerships*

Changes within individuals extended to their respective structures and, further, between structures partnered by the UNPRPD.

I think there are, you know this project has one successful achievement. That is to join, to put at the same table some of the public actors that don't speak to each other about this subject about human rights of persons with disabilities. It is a success to see them speaking together about these common matters. Because each one has one perspective in one function in terms of political or social action. They have one piece of the picture. And the project, joined them – put them in the situation to dialogue.

The same UNCT representative explained the value of dialogue across partnerships: 'This allows or provides structure to make it work'. The participants in this study, nearly all key focal points in the project, ended with optimism for the future of disability in Uruguay. The UNPRPD inspired progress outside the initial scope of the project, led by the internal growth of the people within government ministries. They requested support from the UNCT for their discussions, initiating an ongoing relationship beyond the two-year UNPRPD timeline:

There have been movements within people that when we share real situations of the weaknesses, the feedback we get from them; it's like, OK let's get together to find the best way. I think even though it may seem like something small, I think that some situations are being put on the agenda that had no visibility in the past at all. I do believe there is intention and political will to think about how to go about it. I don't know when, but at least we do have the will.

From the very beginning of the project, the same actors said we are working together, but we don't want to go beyond some of the rules we have. Some of the policies we have. And now they are working at least to discuss these policies – the tools we have to measure – for example – the disability [determination assessment]. So it is very interesting. The dialogue – to set up the dialogue [was] productive, not just to share.

The UNPRPD project engaged external partners spanning a range of hierarchical positions and set out to address sexual and reproductive health and gender-based violence and improve systematised disability data in Uruguay; however, the UNPRPD focal points ended up undergoing a paradigm shift towards disability rights as a result of the project. The shifts reported as significant were largely internal, seen as the foundation from which to build external change,

such as securing the importance of disability inclusion in policy and future programming among powerful actors. Dialogue between structures began as a practical communication tool for the defined project pillars and led to a working group of several government ministries extending an invitation to the UNCT on a supplementary line of work. This line of work was initiated between government sectors and the UNCT as a result of the UNPRPD project, passing down the absence of disability representation from one project to the initiation of another. The maintenance of hierarchical relationships is a durable force, even in projects designed to be participatory. Many participants felt internal growth was important but too abstract to have achieved ‘real change’ for Uruguayans with disabilities: highlighting the divide between the collective impact of key individual’s paradigm shifts, the structural operations of affiliated institutions, and the social conditions facing persons with disabilities.

### **Conclusion**

Scholars have theorised about creating intentional change over the years, and similar frameworks have been applied within organisational frameworks called programmatic Theories of Change. In the case of the UNPRPD, the design aims to leverage the strengths of existing hierarchies by including CSOs/OPDs in the same conversations with government and UNCTs. The aim is that hierarchies can be useful to implement targeted changes to social systems. The case study in Uruguay provides a real-world example of the theoretical implications of group-based hierarchies, the effectiveness of ToCs, and role capital plays in identifying and ‘unfreezing’ restrictive forces to implement social change. Each theory has strengths and weaknesses, which were explored in the UNPRPD Uruguay project, distinguishing theoretical change from what happens in practice.

### **Limitations**

Change is dynamic, and this data was collected during a one-month period. Further case studies over time will provide deeper context to the participant responses during various stages of project implementation. Additionally, census data is known to be imprecise, particularly the enumeration of persons with disabilities. This study provides only one case example of theory in practice from the UNPRPD global programme and cannot claim to reflect the broader phenomenon.

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Article

# Participation, Legal Capacity, and Gender: Reflections from the United Nations Partnership on the Rights of Persons with Disabilities Project in Serbia

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**Abstract:** The United Nations Convention on the Rights of Persons with Disabilities (CRPD) establishes that people with disabilities shall enjoy their human rights on an equal basis with others. Those rights include the right to legal capacity and to protection against discrimination, including intersectional and multiple forms of discrimination on the basis of disability and gender. In an effort to support the realisation of the CRPD, the United Nations team in Serbia undertook a project to address the implementation of these rights under the UN Partnership on the Rights of Persons with Disabilities (UNPRPD) programme. Namely, by bringing together stakeholders from the UN, government and civil society, the UNPRPD project in Serbia sought to create structural changes to uphold the rights of people with disabilities. With a view of understanding the process of change within, rather than the outcomes of, this UNPRPD project, twenty-eight semi-structured interviews were conducted using the Most Significant Change Technique (MSCT) with key stakeholders involved in such a project. The interviews were analysed using Interpretive Phenomenological Analysis (IPA) to preserve the unique and diverse perspectives of participants who had differing roles across the project. The analysis allowed us to identify a number of facets of the process that facilitate structural change: coalition-building events; strengthening stakeholder capacity and relationships; the participation of persons with disabilities; and innovation in terms of what made the project significant, novel and in itself a change. All these facets are discussed in this article, with the purpose of supporting global efforts in alignment with the CRPD. On the whole, this article aims to support a better understanding of disability-inclusive development projects in line with the CRPD and to give evidence on how countries may begin to tackle the structural exclusion of persons with disabilities in society.

**Keywords:** disability; CRPD; UNPRPD; civil society; United Nations; legal capacity; gender and disability; structural change



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## 1. Introduction

The United Nations (UN) adopted the Convention on the Rights of Persons with Disabilities (CRPD or ‘the Convention’) in 2006. The CRPD is considered a groundbreaking treaty, which ‘sets out explicitly the many steps that States must take to create an enabling environment so that persons with disabilities can enjoy authentic equality in society’ [1]. The CRPD recognises that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’ (Article 1(2) CRPD) and revolves around the key principles of dignity and autonomy, equality, accessibility, and participation [2,3]. The CRPD also values the diversity of persons with disabilities. In fact, Article 3(d) CRPD includes ‘respect for difference and acceptance of persons with disabilities as part of human diversity and humanity’ as a general principle [3].



In the sixteen years since the adoption of the Convention, many States Parties have struggled to amend their laws, social policies and practices to align with the broad-ranging obligations of the CRPD and to allow full participation of people with disabilities in society. In 2011, the United Nations (UN) established an interagency programme, i.e., a programme managed by and funded through an array of UN agencies, including the UN Department of Economic and Social Affairs (UN DESA), the World Health Organization (WHO), World Health Organisation (WHO), United Nations Development Programme (UNDP), United Nations Educational, Scientific and Cultural Organisation (UNESCO), United Nations International Emergency Children's Fund (UNICEF), and the organisations involved in the Serbia project: International Labor Organization (ILO), United Nations Population Fund (UNFPA), UN Women and the Office of High Commissioner for Human Rights (OHCHR). This programme, named Partnership on the Rights of Persons with Disabilities (UNPRPD), aimed to provide support to select countries as they begin to implement various aspects of the CRPD.

Since its inception, the UNPRPD has aimed to initiate change to normative structures that exclude and create barriers for persons with disabilities accessing their human rights [4]. Being present in 39 countries and 3 regions at the time of this study, the UNPRPD has supported a range of diverse initiatives and projects [5] and provided technical expertise to bridge government sectors with civil society and build capacity while addressing human rights concerns that are specific to certain domestic contexts [4]. According to the UNPRPD Strategic and Operational Framework [4], the United Nations Country Team (UNCT) must work as part of a tripartite partnership with persons with disabilities as rights holders and members of civil society and also as equal partners with government throughout the project cycle. The partnership approach is a defining feature of their programmatic Theory of Change (ToC), whereby the UNPRPD introduces technical expertise in collaboration with key actors to promote normative environment reform, capacity, and coalition building as levers of change to realise disability rights at the structural level [4].

While the UNPRPD is a significant cross-cutting programme, it has also unveiled challenges to the provision of technical expertise as comprehensive as the CPRD and has resulted in initial phases of programming focused strongly on the agency specialisations available within the local UN Country Team (UNCT) [6,7]. For example, in countries with UN Women and UN Population Fund (UNFPA) agencies on site, activities were largely focused on sexual and reproductive health (SRH) and gender-based violence (GBV) and would be quite different from those countries in which there is the on-site presence of OHCHR, which focuses on human rights [6]. Projects that stemmed from the availability of UN expertise rather than from initiatives already being led by Organisations of Persons with Disabilities (OPDs) struggled to find civil society partners focusing on the same things [7]. Previous work has also shown that this distinctive tripartite element of the UNPRPD process—identifying, engaging, and unifying key diverse stakeholders, often for the first time—can present challenges for implementation activities [7].

Serbia signed the CRPD on 17 December 2007 and ratified it on 31 July 2009 [8]. As part of the Convention reporting procedures, in several sections of its Concluding Observations published on 21 April 2016, the UN Committee on Rights of persons with Disabilities (the CRPD Committee) found little evidence of the true conditions of persons with disabilities in their daily lives in Serbia [9]. The Committee provided general recommendations, noting exclusionary laws and bylaws, insufficient training and awareness of rights, insufficient participation of persons with disabilities in decisions affecting them, and lack of action to reduce discrimination and uphold the rights enshrined in the CRPD. While the CRPD Committee highlighted large, systematic barriers, little guidance on how to implement or initiate structural change towards realising disability rights exists in the literature today.

Against this background, this article reflects on one project under the UNPRPD programme in Serbia and aims to explore the generative and open-ended research question: Has the UNPRPD programme triggered structural change in Serbia, and if so, how? Serbia provides a meaningful case study, as the primary activity for the UNPRPD project

was to address longstanding discrimination and marginalisation faced by people with disabilities by addressing reform of national legislation permitting the deprivation of legal capacity on the basis of disability (Serbia's Family Law) to align it with Article 12 CRPD, as well as efforts to address Article 6 CRPD regarding the rights of women and girls, and Article 27 CRPD relating to employment. Article 12 CRPD is difficult to implement for a myriad of reasons, and this article was targeted in only 2 of the 36 UNPRPD country projects selected for funding across three rounds of the UNPRPD programme [6]. The UNPRPD project in Serbia established an inclusive and meaningful process, which might constitute a significant example of how to initiate such change away from deprivation and towards a rights-based model aligned with the CRPD. As such, it could become a reference point for the global community in realising the rights of persons with disabilities provided for in CRPD. In that regard, this contribution, while building on existing literature on CRPD and disability rights, does not intend to carry out a legal analysis. Rather, it is based on qualitative methods to identify what supports structural changes. In particular, as the result of rigorous qualitative research, this article aims to support a better understanding of disability-inclusive development projects in line with the CRPD and to provide evidence-based research on how countries may begin to tackle exclusion at the structural level.

After these introductory remarks, this article is structured as follows. The Section 2 provides an overview of the relevant CRPD provisions found in the UNPRPD project in the Serbian context, followed by the research methodology in Section 3. Section 4 provides the results of participant interviews across stakeholder groups categorised by emergent themes. Finally, the article closes with key insights around participatory processes and twin-track programming found in the Serbia project to tackle structural and sensitive issues such as legal capacity and intersections with gender in disability-inclusive development.

## 2. The UNPRPD Project and the Serbian Context

The CRPD Committee recommendations informed the project proposal to the UNPRPD, and Serbia was selected for the programme's second round of funding over two years, between 1 March 2018 and 28 February 2020, focusing on three pillars of work. First, the UN Country Team (UNCT) led by OHCHR sought to amend the legal capacity provisions included in Family Law regarding individuals with intellectual and developmental disabilities (IDD). The second pillar of work focused on the rights of women and girls, specifically sexual and reproductive health (SRH) and peer mentorship. The final pillar of work was smaller than the first two, focusing on increasing the capacity of both the labour market and the workforce of persons with disabilities. This article focuses particularly on activities concerned with the first two pillars. It recognises that legal capacity reform is fundamental to realising other rights enshrined in the CRPD, although amending Serbia's Family Law does not in itself uphold other rights. Having legal capacity does not guarantee employment, although a lack of legal capacity does restrict such a right. An amendment to the law in Serbia would 'open the door', but not in itself guarantee change. This is an example of the sort of 'structural change' the UNPRPD seeks to achieve, where the 'rules of the game' change to allow for social systems to operate differently [10,11], such as individuals with IDD participating in their own decision-making about employment. The 'rules', according to social theorist Pierre Bourdieu [10,11], define what is normative in a social system, but they do not necessarily determine the outcome. The CRPD effectively seeks to change the 'rules', whereby nations sign and ratify new sets of rules, but each society may have different interpretations of how the Articles will be applied in their country context. Thus, issues of legal capacity may result in unique barriers, for instance, for women with IDD in a particular country. This may, for instance, require gender-specific interventions in the case of Serbia's Family Law and beyond.

### *2.1. The First Pillar: Legal Capacity*

Under Article 12 CRPD, perceived or actual deficits in mental capacity must not be used as a justification for denying legal capacity (both legal standing and legal agency), and people with disabilities are entitled to equal recognition before the law [12]. It envisages the shift from the substitute decision-making paradigm, whereby a family member or appointed guardian makes decisions for an individual with an intellectual or developmental disability (IDD) without direct input from the person in question, must be abolished in favour of supported decision-making, keeping individuals with IDD at the centre of their decisions by providing support to help them make choices [2].

The situation of people with disabilities in Serbia has undergone review by the CRPD Committee, which, in line with its General Comment No. 1, clarified in its Concluding Observations that any laws that allow the full or partial deprivation of legal capacity on the basis of disability and function violated several articles of the Convention [9,12]. As of 2016, Beker and Milosevic identified more than 30,000 individuals deprived of legal capacity in Serbia (MDRI-S 2016), 93% of which had full deprivation and only 7% had partial [13]. Deprivation of legal capacity is a legal denial of personal decision-making and entails the violation of several human rights, such as the right to marry, be employed, possess and manage financial resources, and have a driver's license. As reported in the Academic Network of European Disability Experts (ANED) Country report on Living independently and being included in the community in Serbia [14], the large majority of adults with disabilities live in institutions. The CRPD Committee has often recognised that violations of the integrity of the person occur in the context of involuntary medical treatments for individuals deprived of their legal capacity, and such violations are reported in the case of Serbia [9,13]. Further, the case for reinstatement of legal capacity is eligible if the reason for removal, such as a disability, ceases [9,13]. In this way, persons with IDD spend years deprived of legal capacity, often in institutions, once a court makes its determination without the opportunity to appeal the decision. In response to the CRPD Committee findings, the scope for the initial round of UNPRPD support focused specifically on Chapter 5, Articles 146–150 of the Family Law [15], addressing the full and partial deprivation of legal capacity, restoration, and decision processes by drafting the amendment and providing technical support. They also sought to shift the national model from substituted decision-making towards a supported decision-making model.

The United Nations Country Team (UNCT—which coordinates UN activities in a country) drove the project with civil society partners who were experienced advocates in the area of legal capacity and familiar with the concerns commonly cited in opposition to amending the law, such as personal and financial vulnerability. Therefore, while the intent behind the mentorship program in the second pillar of work was not explicitly to reinforce efforts to amend family law, legal capacity was always in the conversation, and participants with IDD were included.

### *2.2. The Second Pillar: Women and Girls with Disabilities*

According to the CRPD Committee, the Convention embraced and put forward a model of inclusive equality, recognising multiple and intersectional inequalities, i.e., inequalities that derive from the intersection of disability with other grounds, such as gender. In that regard, the CRPD includes a provision for women and girls with disabilities (Article 6). Article 6 CRPD recognises that women and girls with disabilities are subject to multiple and intersectional discrimination and requires States Parties to take measures to ensure them the full and equal enjoyment of all human rights.

While violations of legal capacity are well-known, evidence of the conditions facing women and girls with disabilities in Serbia lacks specificity, resulting in general recommendations from the CRPD Committee in their Concluding Observations [9,16]. The recommendations included broadly incorporating women and girls with disabilities in policy development and strategy, active prevention of population-specific discrimination, participation in development projects, and investment in gender-equality-related program-

ming [9]. Interventions were nonspecific, recognising the multiple forms of discrimination at the intersection of gender and disability. In this respect, the CRPD Committee's recommendations align with those of the Human Rights Committee, which monitors the implementation of the International Covenant on Civil and Political Rights (ICCPR) [17], which recommends raising awareness around gender equality, protective measures for vulnerable groups (e.g., single mothers with disabilities, women with disabilities deprived of legal capacity), and implementing gender equality as mandated in international treaties.

Discrimination on the basis of gender and disability, such as the deprivation of legal capacity, can affect all areas of life, having a knock-on effect on the enjoyment of all human rights.

### 3. Background, Materials, and Methods

#### 3.1. *Situating the Study*

There is an array of disability law scholarship on the CRPD and on its transformative potential [18], and several academic publications and journal issues are addressing various aspects of international and European disability law [2,19]. A range of articles have addressed the normative content of Article 12 CRPD and the challenges it brings about [20,21], and some authors have approached this provision from a critical standpoint [22]. Article 12 CRPD has been considered a 'controversial' legal norm [23], but it has also been deemed revolutionary [24], and commentators have addressed legal capacity reforms (or lack of reforms) in several countries [25]. Similarly, legal academic commentators have addressed intersectionality as well as the intersection of gender and disability as grounds for discrimination [26]. This article, while taking into account that legal scholarship, adopts an interdisciplinary approach and is based on qualitative methods, as detailed below.

There is a wide range of socio-legal and disability studies on inclusive processes and the participation of persons with disabilities in policy-making, with notable case studies being presented [27]. However, so far, no studies have specifically focused on processes supported under the UNPRPD initiatives, and literature on Serbia is also limited. Concerning the latter, alongside policy reports and studies, such as ANED's ones, few studies in the English language have addressed the situation of people with disabilities in Serbia. Those studies adopt discrete disciplinary perspectives and often focus on specific issues. For example, several recent articles discussed the situation of children with disabilities [28,29]. In the context of broader analysis, scholars highlight that people with disabilities remain at the margins of Serbian society and experience structural discrimination through segregation and institutionalisation [30].

On the whole, this article adds to the current multifaceted scholarship in many respects. First, as noted above in the introduction, this article reflects on one project carried out within the remit of the UNPRPD programme in Serbia, highlighting the strengths and weaknesses of those international initiatives. Further, it sheds light on a country that remains underrepresented in terms of disability literature in the English language, although it does not entail a legal analysis of Serbian Family Law. Further, by using a methodology, as described below, that is chiefly qualitative, it allows us to reflect on what is identified as facilitative of structural change. It hence serves as an important case study to gauge a better understanding of participatory projects, such as those initiated under the UNPRPD, and how these projects allow initiating structural change.

#### 3.2. *Materials and Methods*

Qualitative, semi-structured interviews took place in Belgrade in September 2019, following approval from the Maynooth University Research Ethics Committee on 2 April 2019. Each interview lasted an average of 60 min. Participants involved in the UNPRPD project acted as representatives of their broader organisation, as the UNPRPD programme requires organisational partnership as a core driver of change. Partners included a variety of OPDs, disability rights organisations, local United Nations country teams, government ministries, and researchers (see Table 1). As such, anyone who played a role in the project

was invited to participate in this study, with particular attention to ensuring the perspectives of key programmatic stakeholders—government, civil society, and UN, were included. Participants were excluded if they were a member of one of the core stakeholders but unrelated to the UNPRPD project. An analysis of participant positionality within each organisation was out of the scope of this study as it sought to understand the model of change introduced by the UNPRPD at the institutional level and the processes behind their tripartite partnership in implementing disability rights in Serbia; however, individual factors that emerged from the data were recognised and shared in the results section.

**Table 1.** List of participants by UNPRPD partnership.

Partnership Entity	Notation	Specific Agency or Organisation
UN Agency (5) N = 6	PUN#	OHCHR (leading agency), UNFPA, UN Women, UNDP, ILO
Government partners (4) N = 4	PG#	Ministry of Labour, Employment, Veteran and Social Affairs, Ombudsman, Commissioner for the Protection of Equality, National Employment Service
Civil Society (8) N = 14	PCS#	Our house, FemPlatz, Serbian Association of Employers, Mental Disability Rights Initiative (MDRI), Iz Kruga, Center for Independent Living Serbia, Forum for Youth, National Organisation of Persons with Disabilities
Other N = 4	PO#	Consultants, persons with disabilities involved in project activities

The UNPRPD project coordinator invited project stakeholders to participate in the study, so to include individuals who worked on the project beyond only those active during the site visit. Participants were all local rather than international representatives of Serbian organisations. Participants were interviewed in this study and labeled with a notation beginning with the letter ‘P’ for ‘participant’, followed by letters representing their organisational affiliation and number in randomised order (see Table 1 below).

The same set of six interview questions was used for all 28 participant interviews, which required a tool well-suited to diverse stakeholders. The Most Significant Change Technique (MSCT; see Appendix A) uses accessible language to prompt reflective storytelling about a given experience with open-ended questions [31,32]. Collecting stories from all participating perspectives involved in the project allowed for a rich understanding of the role stakeholders play in realising Article 12 and Article 6 CRPD from this project. The first two questions were designed to gather contextual data about the interviewee’s institutional role in the project and how they came to be involved with the UNPRPD. Next, the heart of the interview prompts the participant to think about activities that felt valuable, asking, From your point of view, describe a story that illustrates the most significant change that has resulted from the UNPRPD projects in Serbia at this phase of implementation. In total, 15 of the 28 respondents shared specific stories, and the remaining participants provided an overall reflection of multiple actions or strategies implemented by the UNPRPD project that resonated as significant. Following the story or reflection, participants were asked about the underlying processes that enabled that change and what made their chosen story so significant. The interview concludes by asking how the UNPRPD contributed to the process and to the desired changes (see Appendix A for the full questionnaire).

This study used the Interpretive Phenomenological Analysis (IPA) to analyse the data. In line with IPA procedures, all 28 interviews were read multiple times and individually reviewed before applying an inductive analysis of responses relevant to the research question. In this way, when all findings were highlighted, they were then organised into categories. The MSCT questions were targeted to inquire about the UNPRPD project, resulting in categories that lined up against the UNPRPD programmatic ToC. Only after clustering responses into emerging patterns was a taxonomy introduced, thus holding any interpretation of the content until after the data were clustered. For example, participants shared stories of government attendance at civil society events on the topic of legal capacity



for the first time. Such stories of new stakeholder engagement as a result of the UNPRPD project were categorised together and assigned the thematic label Multiple Partners. This title was selected from the language used in the UNPRPD Programmatic ToC to align results with the activities designed to trigger a deeper level of change to better understand the programme from a process perspective. The combination of MSCT and IPA allowed for open, generative results beyond typical project metrics (such as the number of workshops held, or assessment of existing policy) from multiple perspectives while maintaining focus on the research question.

#### 4. Results

The 2016 UNPRPD Strategic and Operational Framework [4] outlined their ToC describing key factors involved with triggering change at the national level towards realising disability rights. Some of these factors reflect emergent themes in the data and provide the headings below, concluding with one additional unique theme (Section 4.4; See Table 2). Recalling the research question, ‘Has the UNPRPD programme triggered the structural change in Serbia, and if so, how?’ findings are organised by coalition building, multiple partners, rights holders, and innovation. Coalition building refers to the collaboration between stakeholder groups, with particular attention to the project’s inception event. Multiple partners reflected the process of strengthening stakeholder capacity and relationships. Rights holders were involved in stories of significant change as a result of the participation of persons with disabilities, including from focus group activities and the peer mentorship program. Finally, innovation was cited in participant stories as part of what made the project significant, novel, and in itself a change. The findings provide a process narrative of change from the perspective of project participants.

**Table 2.** Research findings categorical definitions against the key factors in the UNPRPD ToC.

Theme	Definition	UNPRPD ToC Key Factors
Coalition building Inception event	The UNPRPD programme aims to align previously siloed stakeholders, such as government ministries and OPDs, to a common goal through the UNPRPD project pillars.	Lever of change
Multiple partners	Project partnerships, including but not limited to the UNCT, government, and civil society.	Key actors
Rights holders Focus groups Mentorship	Persons with Disabilities and their representative organisations; CRPD Article 4.3	Key actors
Innovation	New theme, not included in the UNPRPD Toc but emergent from the data	NA

##### 4.1. Coalition Building

Five of the fifteen interviews that responded with specific stories reflected on the engagement between project partnerships such as meetings, focus groups, and other project activities that bridged previously siloed groups key to legal capacity reform, particularly when government officials were in a shared space with OPDs and civil society organisations specialised in a legal capacity. The five stories depicted either working group sessions or the project inception event, suggesting multiple partnerships between key stakeholders identified by the UNPRPD had a noteworthy and positive effect on driving the targeted changes.

The UNPRPD began with strategic steps to establish the working group before pitching ideas for the project pillars. A participant from the UNCT reflected on the step-by-step process. PUN3 shared:

*First we found out who was working on the draft and the minister appointed to work together, which at that point did not include civil society. There was no indication that they wanted to amend the part about legal capacity because the main agency working was on children's rights—the train had already started leaving the station, so we recognised the momentum. Then we insisted to bring to the table other stakeholders in the area: the Ombudsman of protection, DPOs (OPDs), CSO, and mental disability rights initiative.*

After connecting with the ministry for involvement in the project, the UNPRPD project ensured civil society was introduced before formally proposing project priorities. Engagement started slowly with incremental invitations across partnerships. While inviting members to join the working group, their participation helped construct the direction of the project toward targeting legal capacity based on participating expertise. Next, OHCHR outlined the support they would provide for amending the legal capacity component of Serbia's Family Law in a meeting with the leader of the working group, making a compelling case for this project over child rights based on the UNCT and civil society expertise available to implement the work. Based on the strategic discussions among key actors, all parties agreed to prioritise legal capacity as the main pillar of work for the UNPRPD project.

The UNCT reinforced the UNPRPD operational requirement to include representative disability organisations during the development of the working group. Some members of the UNCT worked in CSOs for IDD and legal capacity before joining the United Nations; thus, they were aware of the local expertise available to invite into the project during the early design stages. The UNCT proposed the project with known contacts, in-depth knowledge of legal capacity, and a roadmap of what could be achieved with the available resources, as opposed to an abstract proposal to such a complex issue.

As the project scope began to narrow towards addressing legal capacity, all of the engaged partners and additional stakeholders were convened to discuss the proposed activities within each pillar of work. Gathering members from different partnerships into a conversation about legal capacity was said to be the turning point for key partners. PUN3 continued:

*We worked on one big closed event to only discuss the legal capacity part, which turned out . . . more than 20 stakeholders and other institutions from the province and republic level. So, I think that was the point where the leader of the working group and the leader of the ministry realised how important it was to so many groups and felt the pressure from civil society—and (they) made a public commitment to address it. Then we had another meeting to actually draft it. Now we are waiting for the final draft to go up (for) public discussion—the last step before the law will be adopted.*

The turning point was not a single, magic moment in which legal capacity was amended or the project no longer required engagement. Rather, it was seen as the early commitment to pursue ongoing work towards amending Family Law to align it with the CRPD.

There were several stages of engagement to implement the project as the UNPRPD programme design intends. Participant PUN4 shared, ' . . . they were not aligned with the CRPD principles. Maybe not ready to work together. So, I think for me, the biggest achievement: now we are much more working on the same goals. UN, civil society, and government bodies.' Thus, the UNCT had to simultaneously align the work to a rights-based framework as mandated in the CRPD while continuing to facilitate discussions around legal capacity reform. The significance of these conversations was not limited to legal capacity but also noteworthy by bringing new, unfamiliar groups into the same room to address mutual assumptions and disability stigma. Participant PUN1 recalled:

*(The) most vivid example in my mind was fights we had at the first meeting between civil society representatives and national employment services. They were fighting, contradicting, doing damage to persons with disabilities (saying things like) 'they do nothing', things like that. And now, I see them without our involvement, they have*

*cooperation on other different projects. So, they respect each other now as partners, and they work together and contact each other.*

Arguments revealed misunderstandings between stakeholders, which the UNCT could then openly discuss to increase system awareness between groups. Many of the stakeholders had not worked together on a joint project before the UNPRPD; thus, inter-agency meetings with the UN as a key connector served to promote the value of each stakeholder and bridge participants in a new way. The same participant continued to describe misunderstandings between partners and their affiliated structures, stating, 'They didn't know about subsidies and support the government was providing. There is support, maybe not the best support, but there is support (such as), adaptation at the workplace, and subsidies for salaries. They have subsidies.' These misunderstandings revealed a mutual misperception of each other, whereby CSO and persons with disabilities were unaware of the available subsidies and services, and those providing the services assumed persons with disabilities were not willing to join the workforce. PUN1 identified the storming conversations that unraveled the long-held assumptions behind employment barriers as most significant, particularly as the clarity and awareness of each other were felt throughout the project implementation that followed. They shared, 'This was individual change, but after the dissemination activities, and they worked with some other organisations, they shared this level of thinking and understanding, so it multiplies.' This is an example of how the UNPRPD transitioned from implementation activities to structural change. The UNCT recognised the impression groups had of one another and seized the opportunity to address the underlying relationship, resulting in a more willing and cohesive partnership.

Some participants were more conservative about the perceived progress between groups than the participant above. PUN1 described specific misunderstandings that could be resolved through a clarifying conversation, whereas the more abstract barriers between stakeholders remained an ongoing effort. From a different perspective, PUN2's story described moderate change after consistent engagement throughout the project activities:

*(We had) several meetings and forums since inceptions, various steering committees, working group meetings, and some events organised by other projects. We had a conference at the beginning of the project marking 10 years of CRPD, and 70 years of human rights. And these different occasions to discuss these issues, all the time, we based our activities and leadership on the CRPD. And we were trying to convince them that this is the road that we should follow. And convince them that we have to work together, and now we are somewhere in the middle, but they have to work together to make real change and make it sustainable.*

Across the stories of partnership building, engagement did have some immediate results but was not limited to the start of the project or the initial invitation to participate. The UNPRPD project in Serbia made engagement an active part of each meeting. The CRPD was embedded in that process, working in multiple ways to align the participating members, become familiar with the obligations of the convention, and aim to increasingly secure a commitment to disability rights amongst the group.

As discussed in previous sections, the UNPRPD ToC key mechanism is the tripartite approach of partnerships between governments making decisions, the persons subject to those decisions and their representative organisations, and technical expertise. In reality, the partnership approach comes at varying levels of readiness. For Serbia's project, the technical capacity was available, known, and engaged. Resource availability and mobilisation are different issues to the perceptions of the OPDs and experts with IDD or their role in projects. The UNPRPD was not the first effort to legitimise disability expertise in Serbia's development work; however, it did contribute to formalising a participatory approach. In this way, participation and legitimisation of OPDs and persons with disabilities were both a strategic operation as well as a project outcome.



#### 4.1.1. Inception Event

Whether the conversations around specific or abstract barriers were noted as significant, the project inception event struck all participants who mentioned it as a very positive symbol of progress. It served several purposes in addition to the declaration of the shared commitment to legal reform as the primary pillar of the project. The event was seen as memorable due to the diverse range of people in attendance. PUN2 described:

*The launch of the project (was a) large expansive conference with head of UN, heads of OPDs, heads of CSO, the Ombudsman office, governments; 250 people from all parts of the project. This was our inception event this was the only way. First of all, we needed to celebrate the 10 years of CRPD. We needed to review the CRPD in the country and reflect to see if it has been implement(ed). We need to motivate and bring on board (the) Ministry of Labour. We need approval from the line ministry—we needed them to say, ‘it’s ok for you to do that’. I would say it wasn’t an illustration of change, but it was very interesting.*

This participant recognised the essential role the government played in the implementation of the project. The UNCT proposed to amend Family Law; thus, one measure of success was in the hands of another stakeholder. The UNCT does not have the state authority to pass amendments and required government cooperation. In other words, government commitment to the project did not guarantee the implementation of activities. As such, the inception served to continue solidifying additional buy-in from key stakeholders even after the project was decided and underway.

The concept of what constitutes change appeared at the end of the previous quote. The storyteller did not consider the inception design, purpose and event as change; however, they continued by sharing the novelty and response to the event as significant:

*(This event was) the first ever—I can testify to this—discussion among all stakeholders about legal capacity reform. The UN was the convening party. (It was the) first time the Ministry of Labor actually came into the panel to present their vision . . . and what has been drafted to this point. Then all experts, academic, UN, CSO and DPOs (OPDs) were all there representing all disabilities. It was, for me, for someone doing legal capacity work for 7 or 8 years. This was the first time in Serbia that legal capacity was tackled, but in a participatory, inclusive and transparent way. (The event) lasted for several hours, and everyone left happy . . . The advisor to the minister, he said ‘I am shocked’, because he did not envision legal capacity at all. He said, ‘you shock me. Please put it on paper.’*

The event resonated with key actors in the ministry, which was previously identified as an important aspect of future uptake. The persistence in stakeholder engagement was a point of achievement and enabled something novel, whether or not it was perceived as change. PUN2 shared:

*Everyone felt they were a part of something that was never in Serbia before. (The) UN kept track of everything that was said. Everybody was there. . . and everyone congratulated the UN for keeping the story alive. This story would not have been kept alive. It might have been done in a closed office in the ministry without anyone knowing and perform some public discussion with no impact. . . and we compiled the inputs and notes, and made a policy document and sent it to the ministry. Then we kept talking with them. For me it was such a big step forward, because it had never happened before. There was no interest in changing the law, and even smaller chance that it would align with the CRPD, and then communicating it with other stakeholders (social care, representative of judges—everyone was there). That has never happened before. I was proud because it would never have happened without us. I felt it was our obligation. No one else was doing it, and no one else could have convened all the partners. So, for me, that was one moment I would circle as an illustration of what we are able to do with joint forces, with focus and expertise.*

As the story begins to wrap up, the participant detailed the role of the UNCT in managing the project throughout different stages of work. 'Keeping the story alive', was the difference between action and plateau, handled through timely documentation and managing the stakeholder connections to facilitate the maintained engagement and commitment to amending Family Law. While the storyteller themselves said in an earlier passage they had been working in the area of legal capacity for many years prior to the project, the UNPRPD propelled the existing capacity and mobilised a network of actors into a formal initiative.

The end of the participant's story looks beyond the scope of the project and on to Serbia's ongoing disability inclusive development. Each focal point exists within a larger structure with a variety of responsibilities. In particular, the UNCT has a long history and several lines of work with government ministries and introduced civil society as key partners starting with the UNPRPD activities. The relationships cultivated within the project were reported to surface outside the project limits:

*We (initially) reacted to a lot of negative reactions from the country ... and we are now involved in drafting the national disability strategy. 3 years ago, a new National Disability Strategy was drafted, and it was the baseline for the new PRPD project, but (it) never got adopted. But we got the project. In the course of the project, we could build the connections with all the partners to help facilitate the new National Disability Strategy. UN is leading the way and securing the participation of civil society, and new national anti-discrimination strategy has a huge disability part. We are hoping to change the law in a matter of a month, then a strategy in the year.*

Just as relationship building led to broader awareness during implementation, the UNPRPD partnership approach and inception created a ripple effect, extending the commitment to disability rights beyond the scope of the project. Participants felt several activities led to wide-ranging and sustainable impacts through the reinforcement of engagement, alignment to the CRPD and broad invitation to relevant stakeholders, making the problem more visible to key decision-makers through inception activities.

#### 4.2. Multiple Partners

Participants shared stories of significant change in both stakeholder and individual levels of engagement. The next section focuses on the eight stories of direct engagement with project recipients, such as focus groups with individuals with disabilities and their families regarding legal capacity, a mentorship programme, and engagement with the general public.

The UNPRPD project recognised the need to bring persons with IDD into the process across all activities. UN agencies partnered with local CSO and OPDs involved in the legal capacity rights of persons with disabilities and hosted focus groups to gather direct input. Four of the stories in this section reflect on the importance of these events and the significance of the response from persons with disabilities and their families. When asked about a story of significant change, one CSO representative shared a conversation they had with parents regarding concerns about retaining their adult child's legal capacity. Parents shared fears around the vulnerability of persons with IDD to punishment for criminal acts the person may not have been aware were violations of the law, risks to financial independence, being taken advantage of, and similar worries. Parents understood the removal of legal capacity as ensuring freedom from potential repercussions by the state. While participants shared the parent's concern and desire to protect their adult IDD child, denying legal capacity also came with fears. Parents reported feeling it was their only option to remove legal capacity and were interested to learn more about alternative protections from the focus group sessions. PCS5 said:

*They were asking really practical questions. What should I do if an old lady wants to marry my son and take his house? We then talk about what alternatives are there. The CRPD has this, but you have to put it in every specific question they ask. Which can*

*be difficult. . . . People have a lot of fears that are not completely grounded. Sometimes you offer them . . . what is already present, because deprivation of legal capacity is not protecting them . . . We go through the academic papers and these processes, and that takes significant time.*

Much like the misunderstandings between stakeholders discussed in Section 3.1, the same was true for the individuals and families interacting with the various protections and legal systems in Serbia. The project worked to translate the rights enshrined in the CRPD by using scenarios brought in by focus group participants. Communicating in an accessible way and in terms specific to the parents of rights holders was seen as an important step in the process.

Conversations went beyond the scope of what legal capacity entails and further into the general meaning of rights in other focus groups with both parents and rights holders. As mentioned in Section 2.1, substituted decision-making and 'best interests standard' are not compliant with Article 12 CRPD and must be reformed to include input from people with disabilities without judgement of those preferences. Human rights are not intended to protect an individual against making 'bad decisions' and, in fact, allow for human judgement. This understanding of legal capacity was noted by another participant as they reflected on a story from a focus group with a parent and adult child with IDD. They spoke about the right to vote, not predicated on whether the vote was informed. PG4 shared from the focus group:

*She asked the girl with autism if she would like to vote, and she said 'yes'. (When we asked for who, and she said the current president. When asked why, she said, 'well because he has a nice suit'. We talked about how that is not a worthwhile reason. And she (the person with autism) pointed out many people vote based on who is handsome and whatnot. (The personal reason behind the vote) is not that important, but it is important that they know about that right and that they want to vote.*

Notions of protection and freedom to participate in civic activities were used for focus group members to discuss the meaning of rights more broadly. The focus groups were opportunities to discuss the nuance of what rights mean in different circumstances that would go hand-in-hand if recognised as equal before the law.

#### 4.3. Rights Holders

Up to this point, participant stories have reflected on strategic engagement and awareness raising as a process of implementing project pillars, particularly between previously opposed groups. In addition to systematic changes, or changes to how things are done, several participants noted the impact on rights holders directly through the practice of including persons with disabilities and their families during the implementation process. The project engaged individuals with IDD in two primary activities: a discussion of legal capacity reform (primarily in focus groups) and a peer mentorship program for women with disabilities. Both were cited in response to the most significant change question.

##### 4.3.1. Focus Groups

Including persons with disabilities as project contributors, or valued partnerships within the project, was in itself a practice of realising human rights during legal capacity reform efforts in Serbia. PCS14 spoke of the focus groups and the effect they had on participants with IDD:

*They were very excited and very interested to participate because it is a lot for them to get some more significant position in this society. So, they were in a position to be recognised in the same way as other citizens who are asked to tell something about themselves. It is a big, important thing for them to be invited somewhere to talk about themselves, personally. Not that they have somebody to talk for them. And they have something to say, obviously.*

Activities where individuals with IDs were directly involved with providing input to the development of the primary project pillar were seen as both atypical to promote

individuals deprived of legal capacity to active voices, as well as reciprocal in benefits for both the UNPRPD project progress and the individuals' capacity to know and advocate for their rights. Building the capacity of self-advocates in Serbia was not an explicit activity targeted in the project; however, the awareness-raising process and conversations with rights holders were brought up as some of the most significant changes, as well as in other areas of several interview responses. Further, individuals with IDD were reported to feel immediate improvement from the act of inclusion. PCS10 shared in another focus group for women on the issue of SRH and GBV:

*... it has already had some benefit for these women because they are very rarely asked to give their opinion. It was good they realised they have a right to share their thoughts—it has had some psychological impact. It was good for these women's psychological senses, and we developed some cooperation with these organisations in different towns.*

A partnering CSO hosted a focus group and proceeded to engage other CSOs outside of Belgrade to expand the scope of their conversations after recognising the impact of sessions for women with IDD. Many of the activities were quickly scalable by civil society without the support of the UNPRPD. Therefore, while the UNPRPD was working to amend Family Law at the national level, the civil society expanded conversations with individuals with disabilities about rights beyond the capital, where project activities were primarily located. As such, this story shows the ongoing commitment held by some project partners to scale their role in disability rights beyond the mere completion of project activities.

The psychological relief felt by focus group participants is at the core of human rights practice. Persons without disabilities ought to be in positions of authority to reform policy, but they also have a rich history of having their rights upheld. Due to the imbalance of power, it is more than the development activities behind realising the CRPD that make it profound, rather it is the moments whereby persons with disabilities were being recognised and treated on an equal basis to others. In this way, the project was rolled out with a strategic, two-year implementation plan that drew some immediate changes through the inclusive processes behind various activities.

#### 4.3.2. Mentorship

The psychological relief mentioned in the previous section was significant due to the participant's lived experiences with abuse and violations of their human rights. Due to the myriad of barriers facing women with disabilities, the UNPRPD piloted a peer mentorship programme with a local women's organisation. The reality of these rights violations surfaced in some of the conversations between an institutionalised resident deprived of legal capacity and their mentor. PCS12:

*Without disclosing something private, the mentee and I had a very complex and difficult process ... Many topics were brought up, and it was work to overcome several obstacles for their living and development. Their life. (I spent) time with them and conversation. It was hard. There were emotional moments. We were scared. We were thinking what could we do when we continue, and what they can get from us in such a complex situation. The best thing was the two of us were a team, and we supported each other, and that gave most of the results.*

Initially, the mentorship approach seemed too small an intervention to combat the barriers of life under the Family Law restrictions. Despite the limitations of what the pilot could and could not do, this story was seen as an example of meaningful change to expectations. Once the relationship became less about fixing and more about the support and connection of mentorship, the design value was able to surface and strengthen the engagement:

*It was difficult to accept the line, the limit (of what a mentor can do). But when you manage to do that ... they do not feel threatened and they do not have the feeling we (have) given up on them.*

Accepting the line' as the participant said, was an important step toward optimising the potential of mentorship. Not all activities were intended to directly amend Family Law, but rather grow the capacity of local self-advocates in support of a sustainable social shift.

#### 4.4. Innovation

Many of the participants, in their stories of change, reported thinking in a new way, innovating, changing direction, and reimagining a nation with support services rather than institutionalisation practices. This was true across levels of action, including individual perceptions of disability, standard processes between government and UN, pathways to enact change, engagement, and interaction. Deprivation of legal capacity remained an issue in Serbia despite challenges from four distinct international regulatory bodies and civil society advocates calling for national reform outlined in Section 2.1. Participants felt the UNPRPD project was an opportunity to do things differently than what had been done in the past. PUN6 shared:

*I think that sometimes in our everyday life and work, we are all the time ruled by regulations and structures and how things were previously done. I think the project actually showed us we shouldn't knock on the doors that are closed. The reason why this stands out—it taught me some things cannot be done in one way . . .*

This participant saw beyond the project activities and into the systems that surround them, making the status quo and underlying processes more transparent. As such, awareness made space for intentionally changing direction. Traditional approaches to disability rights implementation were unsuccessful as the project launched in Serbia, so while they were changing the operational approach by including OPDs and experts with disabilities, participants also began to rethink norms. Some interactions with persons with IDD and their families brought a greater awareness of disability stigma and ableist paradigms. One representative from the UN shared a moment that triggered her own rethinking:

*I had an opportunity to meet people in institutions and (some parents). What was very striking to me was a mother who has a daughter (with IDD) . . . and the mother showed she really has to think outside the box. For example, when her child has the desire to be in love, but she is just imagining this love, and the mother has to let her just imagine and talk to her. For her intellectual experience, it is better to let her feel that love. It is very encouraging and brave of that mother.*

The participant continued to reflect on the assumptions about persons with IDD that perpetuate exclusion despite their concerns posing no threat, outside of breaking normative expectations. Questioning old paradigms of disability translated into communicating the implementation activities from a new, positive frame. PUN6 felt a change in tone was effective in engaging the non-disabled stakeholders sharing:

*Sometimes you have to find ways to talk about serious topics. If you organise a workshop on sexual and reproductive health or gender-based violence, no one shows up. We have to have innovating ways, and that is good because then you include more people, and no one feels you are targeting them. We didn't approach this topic from the negative—what is not working. If these NGOs when they start talking about problems and what is not working in the country by people (we) all know. But this came from a positive tone—what can be strengthened.*

Just as the UNCT and OPDs persisted with the engagement of government stakeholders over the project lifecycle, key actors in the project recognised aspects of conventional development activities that created barriers to broader engagement and uptake. Legal capacity deprivation and multiple marginalisation on the basis of disability were brought into the conversation as generative, dispelling the idea of an unchangeable status quo by spotlighting the value and momentum possible from participating in project activities.

Finally, the activities also introduced new processes and technology that had not been used previously. Civil society and UN Women were working on outreach and growing their connections with the Serbian community. Social media had not been utilised due to

inaccessibility, limiting their outreach. The team sought solutions to make use of major networking channels such as Facebook to promote and educate the public about women with disabilities from a strengths-based perspective. PUN6 explained:

*Because of the budget, they found an app that can make things accessible so she is trying to make a post accessible to them . . . This really opened to many different angles of how you can improve everyday life. gain, it is a small thing, but you want to be open to new options.*

The project team used accessibility practices to model and include more members in their outreach. Thinking outside the traditional accessibility services, such as captioning, and towards low-resource and easily implemented technologies work to mainstream participation regardless of activity or target population. The participant reflected on what was seen as a ‘small change’, and it shows more inclusive thinking from all ends of the project.

## 5. Discussion

The UNPRPD project in Serbia primarily sought to amend Family Law in recognition of individuals with disabilities (primarily IDD) as equal before the law, thus triggering a cultural change and piloting a peer mentorship programme for women with disabilities. It also sought to strengthen the capacity of civil society and government participation in disability rights implementation through partnerships and project activities. Delivering activities at both the root and lived experience of disability exclusion with such a stigmatised population required deep engagement and new ways of thinking.

Members of the UNCT used their knowledge and established momentum from local organisations to drive project pillars by shifting the attention from children’s rights to legal capacity with a strategic set of activities. The presence of OHCHR and the accompanying technical expertise of the CRPD and legal capacity not only made use of the CRPD Committee recommendations but also the social networks among human rights professionals in the country. Within a strict two-year timeline, Serbia’s local experts were positioned to support engagement and persuaded the redrafting of sensitive legislation. These careful strategies illustrated what reform would look like in practical terms. The combination of knowing the history of the selected issues, ideas on how to proceed with the UNPRPD support, and simultaneously developing early steps to initiate future reform, all while being open to rethinking unsuccessful norms and processes, made the UNPRPD project in Serbia effective in the eyes of participants.

Importantly, the most significant changes revolved around stakeholder partnerships, as the UNPRPD ToC outlined, but more specifically, stakeholders that bridge across lines of expertise. Section 2.2 touches on Bourdieu’s theory of ‘rules’ by which things are done. Prior to the UNPRPD project in Serbia, the longstanding efforts to reform legal capacity were advocated for in stakeholder silos, and recommendations on intersectional discrimination on the basis of gender and disability were outlined with generalised guidance. These cycles were interrupted through relationships, or social capital, bridged by the UNCT. Expertise was not divided by the strengths of each institution as the ToC broadly intended, whereby OPDs infuse the disability lens, UNCT with programmatic expertise, and governments with national leverage. Instead, the UNCT had previous engagement and knowledge in the area of disability and legal capacity, the CRPD, as the core implementing body, resided with OHCHR and personal connections. Likewise, civil society participants had rich human rights and CRPD expertise. This type of partnership is difficult to establish at scale for a global programme but underlaid the significant changes reported across the project. Further, the familiarity with persons with IDD and their representative organisations within the UNCT contributed to a novel and participatory design. While it upholds the critical role the United Nations can play in supporting countries to trigger legal and normative change toward the CRPD, it prompts reflection on whether or not the project would have had the same successes if different individuals were participating on behalf of the UN, even within the same agencies.

The project concluded on 31 December 2020 with the new disability strategy and Family Law amendment drafted, however without formal adoption. As of December 2022, they continue to await enactment by a new Ministry for Human Rights and Social Dialogue that replaced those engaged in the project. Serbia was selected for a new project from the UNPRPD in 2022 [33], led by UN Women, and activities are yet to be determined. Given the most significant changes were the result of key actors with a shared vision and the UNCT 'keeping the story alive' through activity-based engagement between stakeholders (Section 4.1.1), individual turnover and a two-year lapse in project support will require more research to fully understand the impact on pending initiatives.

## 6. Conclusions

Based on the findings of this research, it can be argued that the UNRPPD programme has triggered change in coalition building and engagement of key actors, as well as the direct participation of persons with disabilities in the project. These are considered levers of change at the structural level according to the UNPRPD ToC and Article 4.3 CRPD, though they have not resulted in the type of impact outlined in the ToC. Normative reform and realisation of Article 12 and 6 CRPD in the daily lives of persons with disabilities remain antiquated in Serbia after the two-year project timeline. This is not to say future reform will not reflect on the UNPRPD project as a critical milestone, and it may prove to have been essential for future countries to model from when these rights are finally realised.

Previous research shows the UNPRPD programme largely supported projects that fall within UN Agency specialisations, and while the OHCHR expertise in Article 12 CRPD and the Convention at large were core to the project, equally so were their relationships with civil society involved in legal capacity activism. This finding needs more research to better understand how the degree of relationships at critical stages of project alignment and implementation play a role in realising the rights of persons with disabilities as a result of UNPRPD projects. For example, are there differences between projects where partnerships with civil society and OPDs were established before a UNPRPD project versus after?

Due to the contextual differences between countries and projects, studying projects over multiple funding cycles may provide a better understanding of how partnerships change over time. Further research can explore if long-term working relationships reduce misunderstandings between government stakeholders and civil society, which was noted as a key turning point in Serbia, or if there is evidence of coalition building beyond the scope of the UNPRPD project. These and other areas of ongoing study will provide more evidence of how the UNPRPD can strengthen and support change at multiple levels and how to put participation and partnerships into practice.

## 7. Limitations

Data were collected during one month in Belgrade and did not include follow-up interviews when the project concluded; it is thus a picture in time whilst the project was in progress. Participants were volunteers, and thus, the degree to which self-selection influenced the results is unknown. Further, this is a single case study in one country, so the results cannot be generalised to the diverse range of country projects within the UNPRPD programme.

Participant positionality was not in scope for the project, such as how the role of the participant's gender, disability status, region, and other such factors impacted the findings. Additional research is recommended to better understand the nested hierarchical impacts within and between stakeholders involved in country projects. Further, the authors of this study are not local to Serbia and, therefore, provide perspective from an external viewpoint.

Finally, the MSCT questionnaire was appreciative and asked specifically about the most significant change. The interview questions did not inquire about all changes, challenges, or barriers. This research aimed to ask about what facilitated positive change and processes that may be insightful for other countries or projects looking to address similar topics.



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## Appendix

Most Significant Change Technique questionnaire

How did you (the storyteller) first become involved with the UNPRPD, and what is your current involvement?

How do you describe your organisation's role in the project?

From your point of view, describe a story that illustrates the most significant change that has resulted from the UNPRPD project in Serbia at this phase of implementation. How do you think this change (reiterate the change event) came to happen (the process)?

Why was this story (use the specific change they stated) significant for you?

How has the work of the UNPRPD and partnerships contributed to this significant change in the country (realising disability rights in Serbia)?

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## The use of a Theory of Change to promote knowledge management and global implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

Authors

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### Abstract

In response to the United Nation's Convention on the Rights of Persons with Disabilities (CRPD), nine United Nations Agencies, along with governments and civil society across 38 countries have participated in the UN Partnership for the Rights of Persons with Disabilities (UNPRPD). This model of partnership seeks to produce structural change that will promote social inclusion. Participants in the programme have attended a series of one-week intensive Knowledge Management Workshops, incorporating a range of social science concepts and methods. We describe one of the outcomes from these participative workshops: the development of a Global Theory of Change for the Knowledge Management component of the UNPRPD. We argue that social science research and practice can strengthen its impact on policy through the use of a Theory of Change approach.

**Keywords:** Disability; policy; United Nations; international development; Theory of Change.

## Introduction

The World Report on Disability (World Health Organisation & World Bank, 2011) estimates that more than one billion people - about 15 percent of the world's population - live with some form of disability; and that in comparison to non-disabled people, they have higher rates of poverty, less economic, political and cultural participation, lower educational achievements, poorer health outcomes, increased dependency and less legal protection. In 2006 the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2006) It acknowledges the historic and contemporary pervasive discrimination, exclusion and marginalization of people with disabilities. It also specifies the duty of States Parties to take all appropriate measures to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms, by all persons with disabilities. The CRPD is the most widely and rapidly adopted human rights instrument ever; and has now been signed by 187 countries, and ratified (made legally binding) by 177 countries. The CRPD complements the commitment to the principle of non-discrimination enshrined in the Universal Declaration of Human Rights, and addresses it in the specific context of disability; moving decisively from a charity to a rights-based model of disability.

Psychological and social science have made significant contributions to understanding and addressing challenges associated with a wide range of disabilities (Goodley & Lawthom, 2006), however this has often been from more of an individual/medical-model perspective, rather than from a social or human rights-model perspective. We have argued that barriers to implementation of the Convention on the Rights of Persons with Disabilities are embedded within longstanding social structures and attitudes that do not give way easily. Often such discriminatory practices — even when not necessarily intentional — are nonetheless ‘protected’ because of the advantages

that accrue to others “the advantage of keeping things as they are, of maintaining the status quo” (MacLachlan & Mannan, 2016, p. 102) Such attitudes and practices may seem “natural,” or “just the way things are”; effectively “othering” those with disability and making them separate to those without disability. Individuals’ attitudes and social structures co-construct each other. Social structures are patterned social relationships mediated through social institutions, such as schools or health services, policies or laws, norms or conventions.

### Disability Models

Disability can be defined in many different ways based on stakeholders’ paradigms and interests, and can lead to different outcomes when translated into development programming. Definitions of disability can also be confounded, often seen when an individual’s impairment is mistaken for the social constructs of disability that surround individuals with an impairment. Exclusion can take on many forms and is both contextualized to the social environment, as well as a global phenomenon with shared attributes such as the topics outlined in the substantive articles of the Convention (e.g., education, employment, right to life). Disability models are commonly referenced either in a binary between the social and deficit models, or rooted in historical and cultural constructs such as the charity, religious and (Cobley, 2018). The rights-based model of the CRPD shares definitional aspects to the social model, whereby the connective tissue lies within the target for intervention: the social environment rather than the person with a disability. This research explores how stakeholders originating from different disability paradigms converge to implement rights enshrined in the Convention on the Rights of Persons with Disabilities (CRPD, the Convention), from a disability rights perspective.

A paradigm's influence on an intervention is important. Countries that have signed and ratified the CRPD may allocate more funding and effort to education for children with disabilities, which is outlined in Article 24 of the Convention. While the state may be putting action to their commitment, it does not ensure compliance. For example, a state can use those funds to build institutions where children are segregated. In this way, development efforts in various sectors mandated by the Convention must also be aligned in the actual implementation. In order to align planned activities in development, disability rights and stakeholders' paradigms must be understood.

There are two main paradigms that function as both a definition of disability, as well as a model for understanding the implications of disability in context. The first considers disability as a deficit or problem strictly within and concerning the individual (Marks, 1997; Levitt, 2017; Winance, 2016). This paradigm has been coined *the medical model*, as the attempts to address disability have largely been 'cure' oriented (Marks, 1997; Levitt, 2017; Winance, 2016). The medicalization of disability is only part of the lens. Terminology such as 'wheelchair-bound' or 'hearing impaired' inextricably link the person to notions of limitation, and are often used to label or define people and groups. Exclusion of people with disabilities may be addressed by making the body 'normal' (homogeneous, or able bodied), conforming the individual to narrow and relatively fixed social norms.

Disability and social inclusion literature highlights the urgent need to shift away from the medical model, and into what is called *the social model* of disability. It is important to clarify the distinct characteristics resulting in harmful practice, as medicine and individual interventions are not wholly problematic. A medical prosthetic or hearing aids are indeed adjustments to better fit a

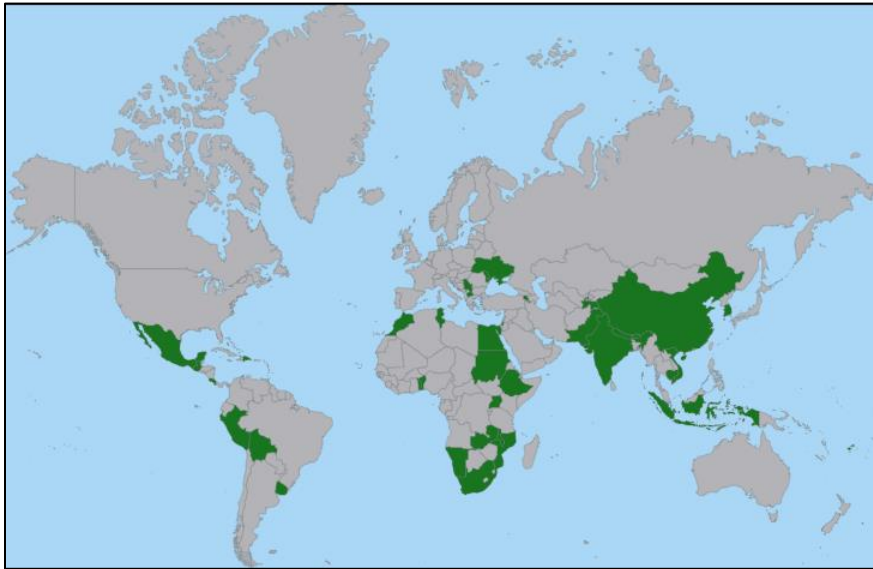
person in their social environment, however recognition of devices as *assistive* rather than curative- or assimilative- are the crux of the paradigm shift.

An alternative approach to disability is *the social model*. While the previous lens saw the problem within the individual, the social model recognizes the problem external to the individual, and relational to the environment (Marks, 1997; Levitt, 2017; Winance, 2016). Aspects of the environment (also known as *structures*) were built for some bodies to participate, but not all (Power, Lord, & deFranco, 2013). The classic example is a wheelchair user crossing a street without a curb cut. This model of disability aims to suggest the sidewalk curb is prohibiting the individual from crossing the street, rather than the capacity of the person with a mobility impairment. Had that curb cut been installed, the individual would have full access to cross the street. A sidewalk design is easy to recognize and requires a straightforward solution, while others are more abstract, such as barriers in policy or education practices. Development action must bear in mind ‘environmental’ barriers are not necessarily tangible structures around us, but also the abstract structures comprised of networks, attitudes, beliefs, and larger social systems.

### [A United Nations Programmatic Response](#)

The UN Partnership to Promote the Rights of Persons with Disabilities (UNPRPD) is a unique collaborative effort that brings together UN organizations, governments, civil society - including Organisations of Persons with Disabilities (OPDs) - and other partners to promote the rights of persons with disabilities through implementation of the CRPD (UNDP, 2016a). The UNPRPD is funded through a Multi-Partner Trust Fund (MPTF; 2018) with contributions from a range of donor countries. The fund and the partnership were established explicitly to address structural barriers to realizing disability rights; and from 2014- 2019 worked in 38 countries (see Figure 1) and with two regional networks (the Pacific Disability Forum and the African Disability

Forum)(UNDP, 2016b; UNPRPD, 2018).



**Figure 1:** The 38 Countries (highlighted in green) in which the UNPRPD has had projects through the first three funding rounds of the programme.

#### Critiquing international frameworks

It is important to remember multiple instruments do not themselves ensure the implementation of disability rights or the success of stated goals. While the institutions are harmonized in their paradigm of disability and inclusive development, the expansion of human rights tools have been criticized for diluting the commitment. de Waal (2003, p. 254) states, “This proliferation of laws is a problem. Many are impractical. Some cannot realistically be implemented. Others have been signed by governments that do not have the capacity or the will to implement them. This is actually a sign of disrespect for the rule of law.” While not all frameworks with explicit mention of disability are human rights law, they are recent ideological changes on top of a system so complex as to become programmatically inefficient, or potentially impossible under current conditions. Evidence of this phenomenon exists in the near complete uptake of the

CRPD, yet innovation and funding for disability inclusive development remain profoundly stagnant. de Waal appreciates the importance of developing and signing such instruments while posing reflection as to the reality of implementation in such tentacled obligations in under resourced and politically unstable countries.

The specific experience of marginalization and oppression facing persons with disabilities make the CRPD both an important paradigm shift in development and equally difficult to action within existing structures. Two popular disability paradigms highlight the complexity of implementing disability inclusion, and help to explain the recent shift towards structural change rather than individual treatment fundamental to realising the CRPD.

### Theoretical background

The UNPRPD indicated several factors considered central in facilitating structural change, shown in Table 1. Many of these have a clear social science and interdisciplinary focus: from cultural norms to inclusive organizations, and the use and development of disability relevant data. The KnowUNPRPD was the knowledge management component of the UNPRPD and it incorporated a range of activities: provision of intensive introductory training and subsequent review, one-week long workshops; personal coaching; a Help Desk providing analysis and feedback for draft applications to the fund; and conducting programmatic research and sometimes providing additional technical and research support (MacLachlan and Mannan, 2016).

Based on the factors central to the UNPRPD approach, this study brings together multiple perspectives to understand their interactions and reflect on the forces involved in disability inclusive development. On one hand, there is the perspective of disability in both local and global constructs. International development, aid and stakeholder relationships bring durable rules and processes to disability, including traditional approaches used to develop the exclusionary social



systems in operation today. The UN and international frameworks provide a compass and metrics for progress- how activities are defined. That said, there may be a different perspective between the planners of activities, and those engaged to provide services for such activities with the participation of new stakeholders- persons with disabilities and their representative organizations. Each individual brings a perspective rooted in their context and organisational affiliation, resulting in new approaches to development projects. The novel approaches to development which include disability have not been studied or validated at the national or global scale, particularly with highly contextualized, cross-cutting projects.

**Table 1:** Factors Central in Facilitating Structural Change

<b>Enabling factor</b>	<b>Thematic priority</b>
<b>Enabling legislation and policy frameworks</b>	Promote the ratification of the CRPD whenever relevant, and the development (or reform) of legislation and policies (disability-specific and not) as well as strategies and action plans
<b>Empowering cultural norms</b>	Reverse stigma, prejudices and negative stereotypes while promoting supportive and empowering attitudes
<b>Access to services (mainstream and targeted)</b>	Enhance access to mainstream as well as targeted services by improving their design and delivery modalities, and by promoting measures that will increase availability and affordability
<b>Access to justice</b>	Increase access to justice for persons with disabilities and the capacity of the justice sector to appropriately

	respond to the specific circumstances of persons with disabilities
<b>Application of accessibility standards</b>	Promote the application of accessibility standards to products, environments and processes, including non disability-specific interventions undertaken by development partners
<b>Adequate Access to rehabilitation, habilitation including assistive technology</b>	Improve access to rehabilitation and habilitation – including assistive technology – by strengthening the availability and affordability of services and improving the design of assistive technologies
<b>Adequate data and evidence</b>	Improve disability-specific data and support research on different aspects of disability as well as the codification of evidence

Several foundational theorists have worked to explain structures, individuals and change to the social environment and can help situate the UNPRPD programmatic approach. Karl Marx understood individuals in opposing and conflicting groups based on the possession of economic capital resources (Marx, 1992). According to his theories, stratification between classes of people is hierarchical and relational- those with wealth and those without. Further, each of those classifications have their own cultures and operate within a shared social field. Emile Durkheim (1993, Giddens, 1971) developed a sociological lens, creating theories of the underlying forces groups exert on their membership. Max Weber brought forth nuance to the relationship between power and how it manages social order, as well as intangible capital such as status (Giddens, 1971; Weber, 1946). Weber saw change and processes within social systems in a feedback loop

with/between agents in power. The individual contains social power, tethering them to structures. His contribution was highly interpretive and grounded relationally, depending on the perspective of a given individual. All of these early theorists uphold the idea that society is constructed rather than inherently natural or determined.

Social order and their underlying forces often organize into hierarchies in which some groups are dominant and others subordinate. Social dominance theory (SDT) is more recent than the work of founding theorists, emerging in 1994 (Sidanius et al). SDT takes the classes or groups of people, forces behind them and explores the historical tendency for societies to arrange in an unequal way based on group characteristics (Sidanius et al, 1994). SDT goes further to theorise how inequality and dominance are maintained through legitimizing myths, or cultural ideas strong and widespread enough to either legitimize one group or delegitimize another, resulting in meaningful resource divisions (Sidanius et al, 1994). Race, gender, and disability have been subject to delegitimization based on cultural myths so pervasive as to become status quo, to name a few.

Myths are constructed and vary by culture. The dominant myths are not unwielded and alone in social ideology, albeit they do hold tremendous power, and thus, often oversaturate opposing myths. Myths that uphold the existing dominant understanding of 'othered' groups are considered hierarchy-enhancing, according to SDT (Pratto & Steward, 2012). For example, the myth that persons with disabilities are noncontributors to society, such as the notion that an intellectual disability is a complete lack of intellect. Or surprise when persons with physical impairments are physically capable of many things. These sweeping myths show up in social environments built by dominant groups that perpetuate and reinforce ablest ideology when, for example, persons with spinal cord injury cannot in fact participate in the workplace if they are

located in inaccessible buildings. Myths become legitimized. Alternatively, hierarchy-attenuating myths offer another explanation for such beliefs. One example is the rise of the social and rights-based model of disability, advocating for a paradigm shift in the dominant myths of disability. Sidanius et al (1994) build on the social construction of group classifications in a shared social field and provide a framework for understanding the distribution of ideologies that preserve inequality in social systems around the world.

Based on the idea that social systems are constructed, it assumes they can also be reconstructed. This brings us to theories of change (ToC), popularised in part by Kurt Lewin (1890-1947). In particular, his conceptualisation of Force Field Analysis (Lewin, 1943) became a major framework for project delivery across many domains (Breuer et al., 2015, 2016), and increasingly so in the international aid and development work context. Lewin is important for his study of fields and change within organisations, both at the individual and group level. The connection is made through a concept called 'life space', referring to the psychology of an individual, given their life experience and environmental position (Lewin, 1936). Before initiating change, fields must first be analysed for their circumstances. He asserted these conditions may either promote or hinder change and can be strategically calibrated, establishing a more tactical approach to his three-step process. He proposed a method for intentionally making organizational change beginning with unfreezing target processes, altering them, then refreezing the new state (Lewin, 1943). Lewin's theories have paved the way for organisations to evaluate field circumstances and develop programmatic ToCs to guide their projects.

Structures and groups are important to distinct from their surrounding field. Rami (2018, p. 8) recognizes the difference between the field of humanitarianism, humanitarian organisations conceptualizing programs and processes, and humanitarians implementing the work- all associated

with creating intentional change. A similar definition is crucial for proper analysis of disability inclusive development. The field of development differs from implementing organisations like the UN and the individuals working within them. Formative theorists provide a preliminary connection between fields, structures and agents; however, the relationship is directly conveyed in Pierre Bourdieu's theories.

Like the other theorists mentioned above, the concept of field is an important container for applying Bourdieu's concepts. According to Bourdieu, fields are numerous, hierarchical and overlapping, each containing their own mini logics and practices (Bourdieu, 1977). For example, the field of disability inclusive development interacts with an established field of international development. One is borne of the other, more established arena, bringing with it the same structures, laws, knowledge, exchanges and sometimes even actors. While fields are constructed by social groups, they are objective in the sense of creating a social reality. People experience real barriers to education, healthcare or social mobility for reasons that were largely determined before any individual interacted in that field. They become durable over time and difficult to change.

Fields contain social structures that are also nested, and positioned based on capital. For example, the object of study in this research is the UNPRPD, which works to assist member states to progressively implement the CRPD through country project support. In studying the UNPRPD programme, it can seem as if it is an isolated subject. This would reduce the analysis to assume the UNPRPD was operationally independent from the overarching structural affiliation- the United Nations system. The UNPRPD is not a dedicated organization, agency or initiative. Many of the UN representatives have previously and currently work in projects outside of the scope of the UNPRPD, and they bring their experiences with them. Much like Lewin's concept of 'life space', Bourdieu defines this embodiment of structural membership as habitus, or the culminating

dispositions ingrained from an individual's social experiences. Importantly, not all experiences and structures are created equal. Some have more or diverse resources valuable to a social system, known as capital.

Capital resources are the forces that determine the power and influence possible to exert on a social system. While Marx focused on economic capital and Weber on status, Bourdieu identified two additional primary forms of capital. The first is social, or the interpersonal networks- knowing the right people. While this concept is now commonplace and integrated into professional life through networking events, internships and conferences, Bourdieu's work brought social networks into light as a form of power (Bourdieu, 1986). Finally, cultural capital is distinguished into three categories. Cultural capital is a form of legitimacy found in objects (objectified), experiences (embodied) and formal process (institutionalized) which hold meaning and convey a social status (Bourdieu, 1986). For example, graduate degrees, stamps in a passport or diamond engagement rings all act as social resources. Unsurprisingly, disability has been systematically withheld from durable capital possession. Objects such as assistive technology and their counterparts- such as stairs or inaccessible computer programmes, have significant meaning. While that meaning may be different for one group to another (wheelchair users feeling freedom of mobility from chairs versus ableist ideas of 'wheelchair bound'), much like SDT shows, the dominant myth is difficult to counter.

Expanding on Sidanius et al, legitimizing myths are concerned with worldviews. Bourdieu also explored frames of reference in the concept of doxa (Bourdieu, 1977). Individuals are informed by their social participation and environment where much is out of purview. Some of this is by design with segregation or the results of historical exclusion. Doxa is much like habitus or 'life space' at the group level. Groups are informed by their position in a field, the capital

resources available and historical status, which lead to norms and beliefs within a given group. While these doxa norms are constructed and reproduced over time, they are often assumed to be natural or given- the way the world is. Much like hierarchy-enhancing myths, doxa and the construction of social spaces reinforce norms to appear universal.

Another important rationale for the application of Bourdieusian theory and analysis is the fundamental cohesion between the ontology and epistemology, and key features of the social model of disability to which development aims to mainstream. Bourdieu's theories of structural change come from a non-dualistic ontological perspective. Rather than the dichotomy of realism or relativism, Bourdieusian theory recognizes the subjective construction of objective realities (Grenfell & Lebaron, 2014; Maton, 2003). Disability exclusion is not the product of an inherent lack of individual value or purely subjective experiences, rather it is constructed through a number of structural interactions over time (Wescott et al, 2021).

Disability development interventions from a rights-based model are not a direct transfer from exclusion to inclusion; rather, they disrupt the forces locking disabled people out of participation in the capital accumulation and exchanges that produce social conditions. Bourdieu's theories and methodology address systems of inequality through the forces driving structural composition, recognising power concentrations in a field resulting from the accumulation or withholding of resources over time (Bourdieu, 1987, Edgerton & Roberts, 2014; Hilgers, & Mangez, 2015; Topper, 2001). When applied to the UNPRPD initiative, this methodology explores how establishing partnerships between structures and resource redistribution can initiate more inclusive societies. If social systems are situated based on the relationships between structures as Bourdieu described (Bourdieu, 1987; Bourdieu, 1990), then the aim of inclusion is to reduce the separation between disability and influential entities that determine their participation (e.g.,

accessible education, employment, etc). While the barriers to inclusion are embedded in an interconnected network of structures, studying the response to interventions between structures can assist in determining if the desired outcomes of increased social participation are being achieved (Wescott et al., 2021). Documenting these responses to development efforts helps to unveil the process of structural change and capture many of the underlying attitudinal and paradigm shifts as a result of local UNPRPD country projects.

Intentional disruption attempts to develop new societal norms and institutionalise them into everyday practice. Structural change, such as the UNPRPD country projects targeting disability exclusion, triggers a reform to what is normal (doxa), and is embodied (habitus) through the individuals subject to what Bourdieu called the new ‘rules of the game’ (Bourdieu 1990, Wescott et al., 2021). Theoretically, if new norms reflecting the CRPD are implemented at the national level and seen in social practice, over time the rights of persons with disabilities will be so common as to be assumed true or natural, and thus the Convention will be realized.

### Theory of Change (ToC)

ToC is a theory-based approach to planning, implementing, or evaluating change at any level (individual, organisational or community). The assumption is made that an action is purposeful. It articulates explicitly how an initiative is intended to achieve outcomes through actions, while considering its context (Ling & Todd, 2015). Thus, it is the end result of a series of critical thinking exercises that aim to provide detailed understanding of the immediate and mid-term changes required for a particular community to achieve a long-term goal (Harris, 2005). ToC is a fundamentally participatory process, involving active engagement by key stakeholders (Taplin & Clark, 2012). Participants articulate their long-term goals, identify the actions that they believe are required for the achievement of these goals, and identify which actions each participant will take



responsibility for producing (Harris, 2005). Connell & Kubisch (1998) have noted that high quality ToCs have three defining characteristics: plausibility (evidence and common sense suggest that activities will lead to desired outcomes); feasibility (economic, technical, political, institutional, and human resources will be available to carry out the initiative); and testability (it is specific and complete enough for an evaluator to track its progress in credible and useful ways). These three qualities help to ensure that a ToC can realistically affect change in a particular setting.

ToC is distinct from sociological or psychological theories, which describe why change occurs, although these may be used to inform the ToC (De Silva et al. 2014). De Silva et al. (2014) have illustrated how ToC can aid the development of interventions by providing a framework for enhanced stakeholder engagement and by explicitly designing an intervention that is embedded in the local context. They have noted that “ToC enables the systematic identification of knowledge gaps to generate research questions that strengthen intervention design” (De Silva et al., 2014, p. 1). Breuer et al. (2016) have stressed that it is important to strengthen the body of literature regarding the practical application of ToC in order to develop our understanding of the benefits and advantages of ToC. The current paper reports such an application.

### Application of Theory of Change

A ToC provides a framework for realistic and flexible planning by applying critical thinking to the design, implementation, and evaluation of programmes intended to instigate change in a specific context (Vogel, 2012). Fundamentally, ToCs focus on how an intervention will work, rather than whether or not an intervention will work (Rogers, 2014). ToC is useful both as a planning tool and for carrying out monitoring and evaluation (Taplin & Clark, 2012). A ToC can be used to develop a project plan in advance, and this can in turn be used as a reference point for

evaluation of the project (Rogers, 2014). During the development stage, outcomes are explicitly defined, and each outcome is assigned one or more specific indicators of success, which can then be assessed as implementation proceeds (Taplin & Clark, 2012). ToCs can also be used to evaluate projects that were developed without an initial ToC, whereby a ToC identifies the specific goals of the project and links these goals to interventions within the project (Taplin & Clark, 2012). Additionally, ToCs can be revised over time as necessary (Connell & Kubisch, 1998). This aspect of ToCs is particularly important in international development, as it allows for realistic implementation of interventions through an inherent acknowledgement that reality often necessitates adjustments to initial action plans. However, the overarching emphasis in ToCs on identifying long terms goals ensures that any needed revisions to ToC will align with an intervention's ultimate desired change.

The identification of rationales and assumptions is a crucial aspect of the development of a ToC (Vogel, 2012). Rationales explain the logic between each causal relationship along the pathway in a ToC, and assumptions explain the contextual background to a theory as well as the justification for the chosen theory (Taplin & Clark, 2012). Specifically, assumptions identify the strategic advantage of a ToC over alternative theories that might be contextually appropriate (Church & Rogers, 2006). Identifying assumptions is particularly important in international development, because it can help to clarify whether the activities and outputs of a ToC are appropriate for influencing change in the specific context in which it is being carried out (Vogel, 2012). Ideally, rationales and assumptions are supported by social science theory and research-based evidence (Stein & Valters, 2012). This can strengthen both the plausibility and the feasibility of a ToC, thereby increasing the likelihood that its stated goals can be realistically achieved (Taplin & Clark, 2012).

Due to the suitability of ToC for results-based planning for international development, it is used increasingly by a wide range of development actors, including governmental agencies, bilateral donors, civil society organisations, and international non-governmental organisations (Vogel, 2012).

Despite the increase in programming or strategy, results are difficult to monitor. Existing literature calls for diverse, quantitative and qualitative impact evaluations to better understand the effectiveness of disability-inclusive development and present methodological challenges to generating such findings, as well as to increase disability inclusion in research itself (Byrne & Kelly, 2015; Burke & Byrne, 2021; Kuper et al., 2020). Kuper et al (2020) recommend the use of a Theory of Change (ToC) to frame baseline and post-programme evaluations, but also recognise the ambiguity that persists in undefined targets, such as ‘stigma reduction’ and ‘participation’ (p. 6). Participation in particular is mandated in the CRPD, yet the process and meaning in varying disability-inclusive development contexts remains difficult to evidence, track and measure for impact.

Similarly, Schuelka asserts of disability-inclusive education, “Measuring the success of inclusive education should go beyond merely counting students to evaluate access, but should include measures of educational quality, outcomes, and experiences. (2018, p. 2)” Most literature on metrics in disability-inclusive development focus on measuring the prevalence of disability in a national population (Wissenbach, 2013; UNDP, 2018; Cobley, 2018), or country case studies finding a greater need for accessibility as a means of participation, organizational awareness or a general lack of disability intersectional programming. These findings are further supported by a systematic review of CRPD Committee Concluding Observation reports on inclusive education across 72 countries, finding widespread gaps in the realisation of Article 24 CRPD (Byrne, 2022).

In the field of research itself, Priestley et al (2010) recommend participation at the ideation and inception stages of a research proposal, having seen most participation of persons with disabilities in the role of study participants. Asserting persons with disabilities and their representative organisations should play a role in setting the agenda for research inquiries further defines participation as including leadership and decision-making authority. Active participation of persons with disabilities are consistently cited as essential to disability-inclusive development and knowledge production (Burke & Byrne, 2021; Lorenzo & Joubert, 2011; Lorenzo & Coleridge, 2019; United Nations, 2006), including in the UNPRPD programmatic strategy (UNPRPD Technical Secretariat, 2016). While there appears to be consensus over key directives such as meaningful participation and non-traditional evaluation and research, there is very little evidence exploring or guiding development processes towards structural change, compounded by the global diversity of disability-inclusive development.

Limited literature on programmatic results in disability-inclusive development has been published, particularly around the development of stakeholder partnerships as enshrined in the CRPD. Coe (2012) reported key learnings from five World Vision projects in the disability domain, including hiring persons with disabilities as part of the development team, increasing positive perception and attitudes of persons with disabilities, consistent awareness raising and strong support at the highest level of stakeholder engagement to expedite progress. A systematic review by Yesilkaya, et al. (2021) identified persistent barriers to support for children with visual impairments, despite the development of facilitating interventions. While literature was limited and Yesilkaya, et al. (2021) call for future research, exclusion remains evident, even in areas where targeted disability programming has taken place. Another example of the Portuguese Disability Movement shed light on the local and historical disability movements as it shaped structural

change, however, the authors noted the continued challenges of implementing policy level changes and reducing poverty (Fontes, 2014).

In another study exploring a programmatic ToC to initiate structural change in diverse communities, Asada et al (2019) found early engagement activities such as alliance strengthening, capacity building and overall readiness for change as critical factors, prompting revisions to their initial ToC framework, especially given short programmatic timelines. Findings highlighted the programmatic need to address readiness for change as an evolving state throughout the project lifecycle and create a distinction between organizational capacity and individual leadership or technical expertise. They state,

The original ToC assumed that intervention support activities- such as still trainings- would improve individual and organizational capacity... however, this part of the ToC did not account for contextual and other factors that can facilitate or impede these processes, nor did it consider the relationship between individual and organisational capacity. (p. 384)

The study identified different forms of capacity, including staff to operationalise and coordinate implementation activities, technical experts and leadership, both high-level decision-makers and individuals “having extensive local knowledge of the community as well as influential partnerships with change agents” (p. 384). This study identifies gaps between a ToC and categories of resources needed for implementation in practice. ToCs are high-level frameworks designed to be open enough for contextual interpretation and alignment with local needs, however, studies such as these offer a meso-level analysis to define broad terms such as participation or capacity that have been problematised in the disability-inclusive development cited above. Similar evidence remains a gap in knowledge for the UNPRPD programme.

Structures refer to the framework of a society, such as policies and laws, institutions, systems and processes that inform a sense of ‘normal’ or status quo. These are often durable and widely accepted. Structural change is necessary to ensure that people with disabilities have equal access to opportunities, resources, and services as enshrined in the CRPD (United Nations, 2019), and are in line with legal frameworks and development priorities.

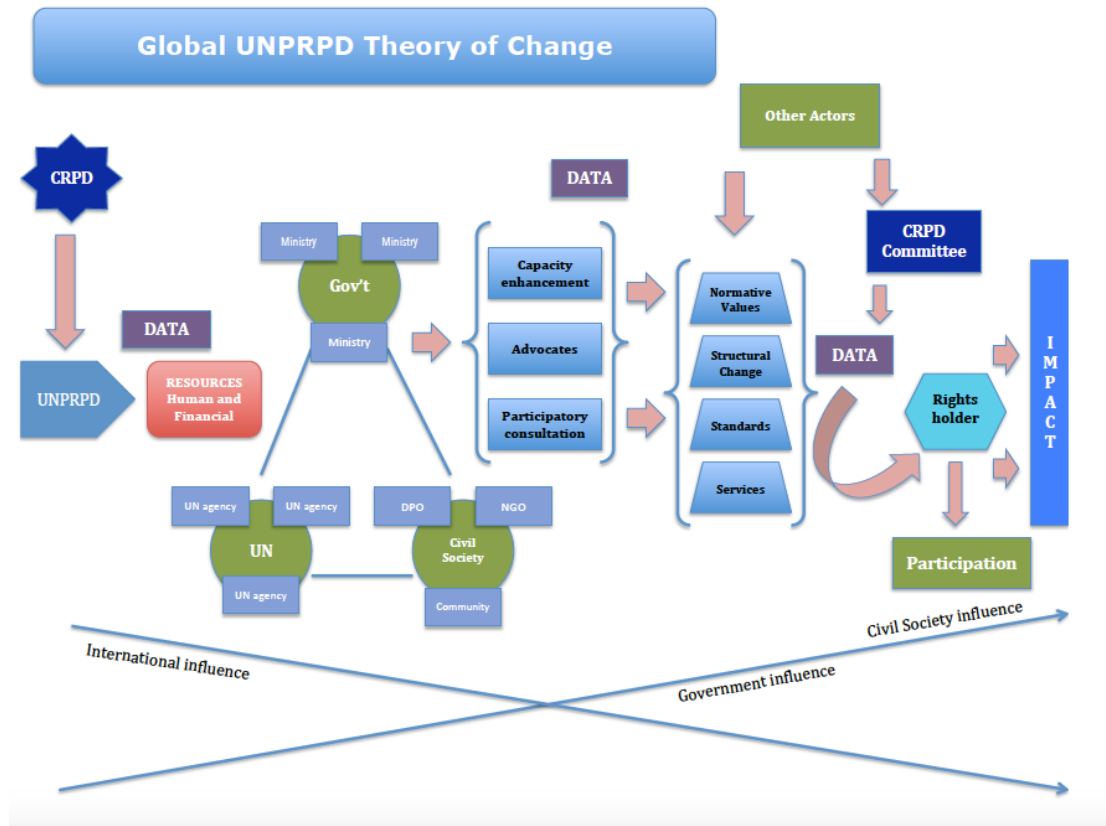
## 2.2 Participants

One of the components of the KnowUNPRPD workshops was to help each participant draft a ToC for the UNPRPD implementation in their own country. Having completed 6 weeks of training workshops with participants from three separate rounds of the programme, we have evolved a global ToC for the KnowUNPRPD. These participants were mostly drawn from United Nations agencies, although the first round also involved a government representative, and each round involved some representation from civil society. On average there were more female than male participants and they ranged from being newly appointed with limited or no knowledge of disability, to senior people with considerable experience and expertise in the disability sector.

At the second workshop for participants in Round Two of the UNPRPD we dedicated a session to co-developing a Global Theory of Change which incorporated the essential common features of different country ToC’s (omitting specific contextual differences and variations). We further presented this Global ToC to participants in the third round of the UNPRPD for further comment and validation of its relevance to their own country ToC development.

## Results

The resultant Global ToC is presented in Figure 2.



**Figure 2:** The KnowUNPRPD Global Theory of Change

Starting at the far left of the ToC, the CRPD is the United Nations Convention on which the UNPRPD is predicated; the Partnership provides human and financial resources, which are justified on evidence (data) informed arguments for the need for structural change in countries which ally to the programme. Moving to the right of the ToC, each country is required to adopt a tripartite partnership between a number of UN agencies (minimum of 3), a number of government departments (more for cross-sectoral projects) and a number of civil-society agencies (which ideally includes a Organisations of Persons with Disabilities (OPDs) and may also include other community or international non-governmental organisations). These country-level partnership projects generally involve some aspect of capacity enhancement (awareness, knowledge, skills

about disability), some aspect of advocating for structural change, and a strong element of participatory consultation with rights-holders (people with disabilities) as well as duty bearers (usually governments). Again, evidence (data) on disability, including prevalence, types, discrimination in employment, access to health or education, and so on is used to support these initiatives. Normative values and social structures are identified as sites of action and need for change, which may involve changing acceptable standards and how services are accessed or delivered. This is likely to involve other actors in these spheres – including businesses, professional organisations, unions and religious groups. These actions should produce further data – ideally compared to a previous baseline – allowing for the testing of assumptions through evaluating indicators of change (e.g. more children with disabilities in school and achieving similar grades to non-disabled children; or more women with disabilities in full-time employment on equivalent remuneration to non-disabled employees) to substantiate whether predetermined assumptions of the change process have been achieved. Rights holders can ultimately report to the Committee on the CRPD and hold their government to account; with the CRPD Committee requiring governments to make changes to implement the convention and improve the quality of life (impact) of people with disabilities. As we move from left to right in the ToC, ‘outside’ agencies (such as the UN) have progressively less influence, and government and civil society progressively more, as they institute the structural changes deemed necessary. Ultimately the ToC charts a process of persuasion to change structural barriers; where multiple levels are used, multiple levers adopted; where networks, personal influencers, incentives, public accountability and many other tactics are used to push forth the strategy of change. Wescott et al (2021) presented a Preliminary Analysis of the United Nations Partnership on the Rights of Persons with Disabilities programme within the context of the Convention on the Rights of Persons with Disabilities and



the Sustainable Development Goals. Here below we provide indicative examples of the work of the UNPRPD in two countries, one from each of the first two rounds of the UNPRPD.

#### Republic of Moldova: Deinstitutionalization and promotion of assisted decision making

The ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the Republic of Moldova in 2010 marked important changes in the field of disability. In relation to deinstitutionalization the Republic of Moldova approved the National Program on the Deinstitutionalization of Persons with Intellectual and Psychosocial Disabilities and the Action Plan for 2018-2026 (2018). In the three years prior to the programme there were over 12,000 complaints from 3,665 people who used (many involuntarily) institutionalized mental health or intellectual disability services in Moldova. Throughout implementation, the four partner agencies had quarterly meetings to assess progress, discuss challenges and potential threats to the successful implementation and strategize further steps. In addition, UN implementing partners used, on a quarterly basis, the already existing governmental platforms, such as the National Council on Disability and the National Council on Child Protection, to bridge and consolidate partnerships across different partner ministries and other state entities directly responsible for the outcomes of the intervention. As a result of the UNPRPD programme, the first Organization of Users of Psychiatry was created and empowered to participate in the promotion of disability rights. Experts participated at every major event in order to guarantee that the voices of persons with disabilities were at the forefront of the project. As a result of UNPRPD support, this organization convened and filed a request for official registration with the Ministry of Justice. The group commented on CRPD Committee Draft General Comment on Article 12: Equal recognition before the law.

UNPRPD enabled work to create independent bodies that will monitor the implementation of the Convention, in line with its Article 33(2)(2016).

The Moldovan government also adopted a national policy on deinstitutionalization of adults with mental health or intellectual disabilities and established Community Mental Health Centres in each of the country's 26 districts. Two years later, the number of beds in large psychiatric institutions was reduced by 40%. In a landmark case, the Court of Justice upheld the right of an 18-year-old woman with intellectual disability to her own supported-decisions (opposed by her parents); and this led to the introduction of a programme to facilitate the legal capacity (decision-making capacity with necessary assistance) for people with intellectual disability. Both the judge and legal aid lawyer in this case had participated in training on the CRPD provided by the UNPRPD project in Moldova. The project also achieved notable progress with regard to inclusive education (see UNPRPD, 2016, for more details of programmatic impact in Moldova and the other countries in the first round of the programme). According to the Ministry of Health, Labour and Social Protection report on the UNCRPD, National Agency for Social Assistance (NASA) reported that at the beginning of the 2020 year in residential institutions were 1696 persons with disabilities, of them 812 women and girls. In the context of deinstitutionalisation and preventing new entrances of the women with disabilities in institutions: - The National Program on Deinstitutionalization of Persons with Intellectual and Psychosocial Disabilities, including women in residential institutions, managed by NASA, was developed and approved, for 2018-2026. During 2017-2020, about 200 persons with disabilities have been deinstitutionalized in community-based services and/or biological/extended families or independent living.

## Mexico: Access to Education and Support for Parents

The UNPRPD programme in Mexico designed and implemented a pilot Model of Inclusive Childcare and Attention for Children with Disabilities as part of the Early Childcare Facilities Program to Support Working Mothers, from households below the poverty line (UNPRPD, 2018). This included providing an inclusive childcare guidebook (early identification and referral, and guidance on day-to-day activities), a didactic activity book (indicating inclusive actions and specific adaptations for children with disability) and a workbook for information exchange (between child-care facilities, families and specialists) and associated training (UNPRPD, 2018). Prior to UNPRPD intervention there were 9,234 facilities providing services for over 308,000 children; but only a third of the facilities included children with disabilities. The new, more inclusive model, was piloted in 405 facilities across nine Mexican States (UNPRPD, 2018). Subsequently child-care facility directors reported an increased capacity to identify and include children with disabilities (from 2.6 to 4.6 on a 5-point scale), to orientate families for inclusion and stimulate children with disabilities (from 2.6 to 4.5) and to implement inclusive planning of didactic activities (from 2.4 to 4.6). The Model of Inclusive Childcare and Attention for Children with Disabilities project in 5,880 childcare facilities of 19 Mexican states, from November to December 2017 (field-work); as a result, new guidelines and protocols for inclusive attention and care reached a total 94,995 boys and 83,049 girls. Direct beneficiaries of the scale-up are 1,572 boys and 1,061 girls with an officially identified disability.

In 2018 the project was scaled up to almost 9,000 facilities. This provision allows for single mothers (or single fathers) to gain employment, knowing their children with disabilities are being well looked after; thus helping to break the cycle of poverty often associated with people with disabilities, and their families (see UNPRPD, 2018, for more details of programmatic impact in

Mexico and the other countries in the second round of the programme). The UNPRPD Project piloted this programme in a sample of more than 400 facilities from nine states of Mexico. In the short term scale-up plan, it will be implemented at a national level with the participation of nearly 5,000 Childcare Facilities Directors, and will thus become a public policy as per the Deputy Director General of Program Liaison, Ministry of Social Development, Mexico (UNPRPD, 2017).

Case study

Discussion

ToCs in international development draw on a variety of sources, including needs assessments, previous evaluations, research, and the perspectives of experts, staff, partners, and community members (Rogers, 2014). We have used this approach, implicitly along with the ideas of Pierre Bourdieu, recognizing the importance of power relations, symbolism, different forms of capital and the general idea that the privileged often prefer to maintain things as they are (Wescott et al., 2021, Wescott & MacLachlan, 2021). While Bourdieu's sociological scholarship was largely focused on social class, it has also been applied to other areas including disability (Byrne, 2018; Wescott, 2021; Wescott & MacLachlan, 2021) and is an important component of political economy analysis (Collinson, 2003). De Silva et al. (2014) suggest that the ToC approach has a number of distinct advantages: it makes explicit causal pathways without imposing pre-defined structure; it is more flexible than linear logic models; it allows for multiple causal pathways, along with interventions at different levels and feedback loops. This, therefore, allows ToC to represent more usefully how complex interventions actually happen. As De Silva et al. argue "ToC is not a sociological or psychological theory such as Complexity Theory or the Theory of Planned Behaviour, but a pragmatic framework which describes how the intervention effects change. The ToC can be strengthened by inserting sociological or psychological theories at key points to

explain why particular links happen” (p.2). While the ToC approach has been used in a range of project contexts (see Connell & Kubisch, 1998, Breuer et al., 2014, Breuer et al., 2016), we are not aware of its previous use at the national level to address social structural change from a rights-based perspective, or for people with disabilities. As other aspects of the KnowUNPRPD project have been described elsewhere (see Wescott et al, 2021; Wescott & MacLachlan, 2021; Wescott et al, 2023; Wescott, MacLachlan & Mannan, 2021) this paper focuses only on the ToC component of this broader programme of work.

## Conclusions

Psychosocial and more general social science skills have an important role in the design, implementation and evaluation of theories of change that seek to challenge and address social injustice at a national or regional level (MacLachlan and McVeigh, 2021). Such interventions should not replace other interventions at individual, family, group or organizational level; but rather complement them and provide a broader planned framework in which the interactive effects of different types and levels of intervention can be collectively harnessed. An appreciation of particular contextual constraints and opportunities will be critical in order to make change happen through resources available in more local contexts. A multi-layered and contextually sensitive application of social science can contribute substantially to change at all levels, including the social structures and institutions that form an important context for how we live.

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**Informed Consent Statement:** Informed consent was obtained by participants of the knowledge management workshop.

**Data Availability Statement:** The data for this study were accessed through the International Disability Alliance (IDA).

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## Assistive technologies are central to the realization of the Convention on the Rights of Persons with Disabilities

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### ABSTRACT

Assistive technologies (ATs) promote participation and inclusion in society, and support access to health, social services, education, work and other important life experiences for persons with disabilities, older people and those with chronic conditions. The Global Report on Assistive Technology, launched in May 2022 by WHO and UNICEF, calls for concrete actions to improve access to AT globally, and recognizes AT as both a means to, and an end itself, in the achievement of rights of persons with disabilities. The UN Convention on the Rights of Persons with Disabilities (CRPD, 2006) is the most widely ratified human rights convention, affirming the right to participation in society on an equal basis with others.

**Purpose:** In this paper, we highlight examples of how AT may play a role in realizing each of the fundamental rights affirmed in the UNCRPD.

**Materials and methods:** We conducted an indicative literature search for relevant literature to each of the substantive articles of the CRPD.

**Results:** Assistive technology plays a critical role in achieving the rights affirmed by the Convention on the Rights of Persons with Disabilities.

**Conclusions:** Ensuring adequate provision of AT by states parties is critical to the progressive realization of the rights of persons with disabilities and to fulfilling commitments made by states parties upon ratification of the CRPD.

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### ► IMPLICATIONS FOR REHABILITATION



- Assistive technology (AT) is critical to enable full participation of persons with disability in society and the achievement of rights affirmed by the Convention on the Rights of Persons with Disabilities.
- Governments and other key stakeholders should endeavour to improve access to AT through inclusive, evidence-informed programs and services.
- Advocacy is required to improve access to AT through universal health coverage.

## Background

The Universal Declaration of Human Rights recognizes the fundamental rights and freedoms afforded to all people, regardless of race, sexual orientation, gender, origin or other status, including disability [1]. For persons with disabilities, these rights are further described and protected through the United Nations Convention on the Rights of Persons with Disabilities (CRPD) [2]. The CRPD was developed in recognition that persons with disabilities experience circumstances which are inequitable and different to people without disabilities, and that it was necessary to have the specific rights of persons with disability defined and enshrined in international law. Persons with disabilities have the same rights as anyone else in society, and these rights require additional protections due to discrimination, to enable full participation in society [2]. The CRPD promotes a human rights model of disability, incorporating the social model of disability [3], and recognizing that individuals who live with physical, mental, intellectual, cognitive or sensory difficulties experience disability in “interaction with

various barriers [which] may hinder their full and effective participation in society on an equal basis with others” [2].

The CRPD defines 50 articles, of which the first five comprise the purpose, definitions, general principles and obligations of states parties, and affirm the principles of non-discrimination [2]. Articles 31 through 50 are primarily administrative, and relate to data collection, reporting requirements, international cooperation, committee structures, signatures and consents; however, Article 32 (International Cooperation) specifically asks for international cooperation among Member States to provide technical and economic assistance, including by facilitating access to, and sharing of, accessible and assistive technology (AT), and through the transfer of technologies [2]. The remaining 25 articles (six through 30) relate to the specific rights of individuals [2]. These rights are broad ranging, and address many aspects of daily life which are critical to promoting participation, well-being, and the inherent dignity of persons [2]. However, it is left to states parties to determine how to ensure these rights are realized within their local

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context, and to enact the policies and programs required to achieve full and equal participation of all.

The provision of AT as a pillar of universal health coverage supports the participation of persons with disabilities in society [4]. *Assistive technology* is an umbrella term, referring to the systems and services related to the delivery of assistive products. *Assistive products* are digital or physical technology which maintain or improve an individual's functioning and independence [5]. AT is central to promoting participation in society for persons with disabilities, or chronic illness and for people as they age [6,7], and it has thus been a key focus for the World Health Organization through the Global Cooperation on Assistive Technology initiative, and other key international organizations. The Global Report on Assistive Technology acknowledges the role of AT as both a means to, and an end itself, in the realization of rights of persons with disabilities. AT has also been demonstrated to be critical to achieving each of the sustainable development goals [8].

Despite a general consensus on the importance of AT by global organizations and experts in the field, estimates suggest only one in 10 has access to the assistive products they need, with an estimated 1 billion people now requiring AT [9] and this number is expected to increase to 2 billion by 2050 due to an increase in survivability of previously fatal conditions in childhood, to greater longevity with non-communicable diseases, and general demographic trends towards an ageing population [9]. This emphasizes that AT also cuts across conventional siloes in health and social services. Given the importance of AT, it is both surprising and concerning that an analysis of States Parties reports on implementation of the CRPD found little to no mention of AT within them [10].

While there is a general understanding among AT users, practitioners and researchers of the critical nature of AT in achieving and realizing rights identified in the CRPD, there is minimal research to demonstrate this link, nor the contributing factors which support or impede AT use and its subsequent potential for promoting rights realization. In this commentary, we argue that AT is central to the realization of the CRPD as a whole, and more specifically, to each of the rights outlined in the Convention. Through an indicative review of the AT literature, we aim to demonstrate how AT can be used to realize each of the substantive articles of the CRPD, bearing in mind the intersecting nature of the AT user and the diverse contexts in which AT is used. We therefore hope this commentary will serve two purposes: (1) to demonstrate the applicability of AT to all of the articles of the CRPD (not only those commonly cited or named in relation to AT) and (2) to catalyse dialogue, future research and policy related to AT as essential to human rights, ultimately improving the overall quality of research highlighting the relationship between AT and the realization of rights.

## Approach

We used a collaborative approach between members of our research team to identify relevant literature for each of the 25 substantive articles of the UNCRPD which outline the specific rights of individuals (Articles 6–30). This approach mirrors the approach taken by Tebbutt et al. in demonstrating the role of AT in achieving the Sustainable Development Goals [8]. Literature was identified based on the collective expertise and knowledge of the field of our team members, and through literature search using Google Scholar or Pubmed to identify key papers, prioritizing systematic or other reviews of the literature wherever

possible. The team has particular expertise in this area, and is comprised of researchers, practitioners, civil society representatives and persons with disability who work primarily in the area of AT, and represents several global regions. The intention of the search was to identify indicative and compelling examples from existing research of how AT is contributing to achieving each of the CRPD articles, and not to complete a comprehensive systematic review or theoretical analysis of the literature. A single example from the literature was selected for each of the CRPD articles to provide a clear and concrete example of the relationship between the AT indicated, and the rights realized. We consciously selected research representing a range of assistive products, and a breadth of geographic regions, across the CRPD articles to indicatively showcase diverse examples of how AT not only links to the CRPD articles, but also how AT demonstrates potential to support their achievement.

## Findings and discussion

There is evidence for the relevance of AT to achieving each of the 25 specific rights-based articles of the UNCRPD. [Table 1](#) lists each of the 25 articles and provides a conceptualization of how AT contributes to their realization, with indicative examples supported by the literature.

The CRPD outlines general principles to guide the interpretation of subsequent Articles, explicitly stating, “Full and effective participation and inclusion in society” [2]. Further, the Committee to the CRPD issued General Comment no. 7 regarding Articles 4.3 and 33.3 of the CRPD, reinforcing the participatory approach used to draft the Convention by obligating States Parties to follow suit in all decision-making, implementation and monitoring processes [38]. Recognizing the mandate to include persons with disabilities in all decisions affecting them, AT becomes a mechanism to achieve both a participatory process in current inaccessible social environments, as well as drive compliance in each of the Articles by their very use. As such, AT becomes essential to uphold the normative principles underlying each Article of the CRPD.

To achieve this aim, the World Health Assembly's resolution WHA71.8 calls on states parties to develop and implement contextually relevant AT policies and programmes within universal health and/or social services coverage [39]. Evidence suggests a very high return on investment for the provision of AT, at a rate of return of 9:1 [40]. The return on investment comes in the form of higher rates of education and employment, leading to greater economic participation, and better health and social inclusion, reducing associated healthcare costs and improving quality of life [40]. The Global Report on Assistive Technology provides an overview of the different aspects of an AT system that are required to ensure access to AT for people in need [41].

Empirical evidence on structures, processes and outcomes associated with AT provision is building and summarized in the Global Report on Assistive Technology. While new research is undertaken, it is important to use existing research to advocate for the changes to AT provision that are necessary to the ambitions of the CRPD to be fully recognized. This paper, for the first time, demonstrates how AT can contribute to realizing each of the substantive rights in Articles 5–32 of the CRPD through exemplars from existing AT research. [Table 1](#) therefore provides a valuable resource for those who wish to advocate for greater attention to AT provision in health and social welfare policy. CRPD rights are not stand-alone, but interlocking, and so [Table 1](#) also supports advocacy for AT in other areas related to inclusion,

**Table 1.** The contribution of AT to the realization of rights outlined in the CRPD.

Article	Conceptualization	Indicative example (study type, type of AT, context)
Article 6: Women with disabilities	Access to AT reduces vulnerability to sexual and gender-based violence, which impact women and girls with disability at a much higher rate than men with disabilities, or the general population.	AT for communication disability, such as hearing or speech-impairments, provided a means to report abuse and receive support services, and to engage in sexual health education and advocacy. [11] (Interviews and Focus Groups, Communication AT, Rwanda)
Article 7: Children with disabilities	AT is critical to supporting the social inclusion, education, and acquisition of developmental milestones in children with disabilities.	AT facilitates social interaction between children with severe disabilities and their peers, enhancing play and social inclusion. There are links between the use of AT and improved activities of daily life outside the classroom, including bathing and feeding. [12] (Literature Review, range of AT, Global)
Article 8: Awareness raising	AT is used by persons with disabilities for self-advocacy, providing opportunities of increased awareness of the experiences and rights of persons with disabilities.	A study of adolescent AT users using cameras with necessary AT to allow them to document daily experiences through a photovoice approach identified a key theme of “photos as a means of consciousness-raising.” [13] (Photovoice, range of AT and adapted cameras, Canada)
Article 9: Accessibility	AT promotes access to the built environment, transportation, and information and communication on an equal basis with others.	Access to adequate ramps and accessible washrooms fosters equitable access to public and private buildings for users of wheelchairs and ambulation aids. [14] (Systematic Review, accessibility technology, Global)
Article 10: Right to life	AT supports individuals in living an enjoyable life on an equal basis with others.	Mobile health apps can help to reduce depression, psychological distress and self-harm, commonly experienced by persons with disability. [15] (Systematic Review, mobile health technology, Global)
Article 11: Situations of risk and humanitarian emergencies	AT service provision which is integrated within emergency response mechanisms helps to ensure the protection and safety of persons with disabilities in situations of humanitarian risk and promotes best outcomes for person who acquire a disability during a humanitarian emergency.	A recent review identifies critical recommendations for increasing access to AT in humanitarian emergencies including the deployment of rehabilitation professionals alongside emergency response teams, and the development of an “AT Provision and Coordination Framework” for humanitarian settings. [16] (Thematic Review, range of AT, humanitarian emergencies)
Article 12: Equal recognition before the law	AT promotes independent management of financial and legal affairs by persons with disabilities.	AT, including the use of voice recognition, screen readers or other communication technologies support exercising legal capacity by persons with disabilities with respect to healthcare and financial decision-making. [17] (Literature review, communication technology, global)
Article 13: Access to justice	AT supports persons with disabilities to participate in justice processes as jurors, witnesses, accused persons, or victims in legal processes.	The International Principles and Guidelines on Access to Justice for persons with Disabilities calls for access to legal advice for persons with disabilities using AT where necessary, and for States to ensure procedural accommodations including AT are available for legal practitioners to communicate with witnesses and clients with disabilities. [18,19] (Guidelines, communication technology, global)
Article 14: Liberty and security of the person	AT provides support for community living and the de-institutionalization of persons with disabilities.	AT is used to support independent choice for people with intellectual disability, increasing options for community living and the de-institutionalization of disabled people. [20] (Commentary, range of AT, global)
Article 15: Freedom from torture, or cruel, inhuman, or degrading treatment or punishment	AT increases freedom of persons with disabilities and reduces the use of harmful or degrading treatments or punishments.	The use of assistive technologies by people with dementia reduced the number of falls, while simultaneously reducing the number of physical restraints used on patients. [21] (Pilot RCT, home independence AT, Netherlands)
Article 16: Freedom from exploitation, violence, and abuse	AT can empower persons with disabilities to report abusive, violence, or exploitative practices.	A mobile computing-based reporting system demonstrates promise for empowering people with intellectual and developmental disabilities to report abuse. [22] (Focus groups, mobile computing, USA)
Article 17: Protecting the integrity of the person	AT provides the tools for meaningful and informed consent for medical procedures and/or research.	Digital technologies may be a more accessible option to support sharing of information and understanding of ideas for children and youth with disabilities in decision making and consent procedures. [23] (Commentary, Digital technology, N/A)
Article 18: Liberty of movement and nationality	AT supports safe migration of persons with disabilities within and across national borders.	Accessible transportation is critical to the safe evacuation of people with mobility disability from conflict situations. [24] (Review, accessible transportation, global)
Article 19: Living independently and being included in the community	AT promotes an equal and effective enjoyment of the right to live independently and participate actively in the community by promoting inclusion and reducing isolation.	AT for independent living includes products which, among others, assist in daily living, communication, computer access, and environmental control systems. [25] (Policy analysis, independent living technology, global)
Article 20: Personal mobility	AT for mobility promotes access to home and community for people with mobility disabilities.	Powered wheelchairs increase life-space mobility for adults and older adults with mobility disabilities. [26] (Cohort study, mobility technology, Canada)
Article 21: Freedom of expression and opinion, and access to information	AT increases access to information for people who require accessible forms of communication and information sharing.	Digital AT, including telecommunication technologies, including captioning apps, have accessible communication for people who are D/deaf and hard of hearing during the COVID pandemic. [27] (Viewpoint, communication technology, N/A)
Article 22: Respect for privacy	Persons with disabilities can exercise individual choices using AT and computing devices, without relying on others, and thereby maintaining their privacy.	Non-invasive brain control interfaces can provide persons with disabilities increased control over mobility or other assistive technologies while maintaining their privacy. [28] (Pilot study, brain control interfaces, Italy)

( continued)

Table 1. Continued.

Article	Conceptualization	Indicative example (study type, type of AT, context)
Article 23: Respect for the home and the family	AT promotes freedom of choice in marriage and fertility decisions.	Access to accessible transportation and health care facilities reduces barriers to reproductive health services for persons with disabilities in low and middle income contexts. [29] (Review, accessible transportation and facilities, low- and middle-income countries)
Article 24: Education	AT supports participation and achievement in education for persons with disabilities.	A systematic review demonstrated that AT can be an “enabler of academic engagement,” and that barriers to AT use “can hinder academic engagement” in higher education settings. [30] (Review, educational technology, global)
Article 25: Health	AT supports access to health services in the community for preventative and ongoing health maintenance.	AT can enable people with disabilities to circumscribe structural barriers to accessing health care, including access to health facilities, washrooms, examination tables, and beds. [31] (Review, accessibility technology, South Asia)
Article 26: Habilitation and rehabilitation	AT is a critical component of habilitation and rehabilitation experiences for persons with disabilities, promoting independence and participation in the community.	AT for cognition increases the efficacy of traditional rehabilitation activities by increasing independent engagement and contextual environments where tasks can be completed. [32] (Narrative review, cognitive supports, global)
Article 27: Work and employment	AT enhances the potential to work and earn a living, and to create inclusive work practices and accessible environments that allow equal participation and retention of workers with disabilities.	AT has been found to reduce the systemic exclusion of blind people from work through enhancing self-reliance, resulting in broadening managerial perspectives about additional jobs that that blind staff could perform. [33] (Case study, mobile technology, USA)
Article 28: Adequate standard of living and social protection	Access to AT is associated with reduction of poverty for persons with disabilities, thereby improving standard of living.	Access to AT in Bangladesh was associated with reductions in capability poverty, an important factor in reducing income poverty and increasing standard of living. [34] (Cross-sectional study, range of AT, Bangladesh)
Article 29: Participation in political and public life	AT promotes access to formal and informal citizenship, including participation in elections.	Assistive technologies allow persons with disabilities access to participate in elections, and those who are blind or have visual impairments to vote privately and independently in general elections [35,36] (Interviews and focus groups, range of AT, Sierra Leone and Zimbabwe)
Article 30: Participation in cultural life, recreation, leisure, and sport	AT allows persons with disabilities to access cultural, recreation, leisure and sport facilities, and to participate in activities in similar ways to their non-disabled peers.	Basic AT promotes sport participation across a range of types of sport and levels of participation. [37] (Survey, range of AT, global)

participation, wellbeing and quality of life; such as education, employment, sport, cultural activities and access to justice.

In some cases, AT is specifically mentioned in specific articles of the CRPD (i.e., A. 20: Mobility, A. 32: International Cooperation) and it is therefore easier to make the link between AT and the realization of those rights. However, there are many cases where AT is critical to the realization of a right, but may not be specifically mentioned. For example, AT can improve access to health services (A. 25) in terms of better physical access, better communication between clinicians and services users, and stronger participation in decision making, including assisted decision making. It has been argued that the experience that persons with disabilities have of healthcare constitutes a very good probe for the overall effectiveness of the health system, in terms of accessibility, equity and right to health [42]. In the context of rehabilitation and habilitation (A. 26), the use of AT is important in both helping people regain capabilities that they may have lost (rehabilitation) and in helping people develop new capabilities that allow them to cope more effectively (habilitation). Some ATs can help people in quite different contexts, for instance, robotic technologies developed to assist older people [43], may also have applications for younger people with an intellectual disability [44].

AT provides more opportunity than simply mediation between an individual and an inaccessible physical or social context. Adolescent’s use of camera footage to document and disseminate conditions of daily life (A. 8), or mobile systems for individuals with intellectual disabilities to report abuse (A. 16) show how AT can also assist in challenging the institutional arrangements of social systems that perpetuate systemic inequality. These technologies in turn can support the momentum from disability

communities to shift paradigms of disability from a charity, deficit or medical model to a social and rights-based model where individuals have and contribute meaningful roles in society.

As explicated above, it is necessary for states parties to develop and implement contextually relevant AT policies and programmes, as inevitably, the unique interplay of sociopolitical, environmental, economic, cultural and historical factors will shape and contribute the potential of AT to realize rights. Future research which explores the degree to which AT contributes to the realization of each of the rights of the CRPD would guide such policy and programing and provide additional rationale for the provision of AT in universal health care systems in order to promote realization of specific rights. In particular, research which positions AT within context is suggested to examine how existing structural and systemic factors can support AT and the realization of rights, or to identify how they impede AT and human rights in the first place. An intersectional perspective of AT users and the contexts AT is embedded within, is one such example which can illuminate the contributory factors that support or impede the realization of human rights through AT and ultimately the provision of AT in universal health care systems.

## Conclusions

The findings of this indicative review suggest the centrality of AT to both achieving the CRPD, and to each of the rights outlined within the convention, ultimately calling for further research and dialogue on the topic to inform equitable policy and programing. Ultimately, enhancing access to AT through universal health and/or social care systems is necessary for states parties to meet

their obligations to the UNCRPD and will ensure persons with disabilities, older people and people living with chronic conditions enjoy inclusion and equal participation on the same basis as others.

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## INFORMATION AND CONSENT FORM FOR RESEARCH PARTICIPANTS

### Information Sheet

**Purpose of the Study.** I am Holly Wescott, a doctoral student, in the Assisting Living & Learning (ALL) Institute, at Maynooth University.

I am undertaking a research study under the supervision of Dr. Malcolm MacLachlan.

The study is concerned with identifying the development of disability inclusive societies over time from the perspectives of key partnerships (e.g., United Nations, Governments, Disabled Persons Organizations/civil society) involved with 3 United Nations Partnerships on the Rights of Persons with Disabilities (UNPRPD) country projects.

**What will the study involve?** The study will involve the opportunity to discuss your organisational role and perspective on local projects for the purpose of understanding structural change made by the UNPRPD objectives. Each interview will last approximately 30 minutes, and use open-ended questions to explore the positive progress of programming to date. There will be a follow up visit for interviews later in project implementation to see how change happens over time, and interview participation in both visits is on a voluntary basis.

**Who has approved this study?** This study has been reviewed and received ethical approval from Maynooth University Research Ethics committee. You may have a copy of this approval if you request it.

**Why have you been asked to take part?** You have been asked to participate in this study based on your organisation's relationship to the local UNPRPD country project. As a primary partnership to the UNPRPD, your organisational perspective is valuable to understanding the larger programmatic impact.

#### **Do you have to take part?**

No, you are under no obligation whatsoever to take part in this research. However, we hope that you will agree to take part and give us some of your time to participate in a one-to-one interview with a researcher. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form and given a copy and the information sheet for your own records. If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up until such time as the research findings are submitted for doctoral evaluation. A decision to withdraw at any time, or a decision not to take part, will not affect your relationships with Maynooth University.

**What information will be collected?** This study will ask participants to reflect on a story or incident that describes the most significant change as a result of the UNPRPD country project, how it happened, and why it is significant from your perspective. These questions will assist in uncovering the deeper processes behind the development of disability inclusive societies, and specifically how the work of the UNPRPD contributes.

**Will your participation in the study be kept confidential?** Yes, all information that is collected about you during the course of the research will be kept confidential. No names will be identified at any time, unless you give explicit consent to allow this. All hard copy information will be held in a locked cabinet at the researchers' place of work, electronic information will be encrypted and held securely on MU PC or servers and will be accessed only by Holly Wescott and Dr. Malcolm MacLachlan.

We would like to place an anonymised version of the data on the Irish Qualitative Data Archive (IQDA) so that other researchers may benefit from access to it, if you agree to so.

No information will be distributed to any other unauthorised individual or third party. If you so wish, the data that you provide can also be made available to you at your own discretion.

*'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority. In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'*

**What will happen to the information which you give?** All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. On completion of the research, the data will be retained on the MU server. After ten years, all data will be destroyed (by the PI). Manual data will be shredded confidentially and electronic data will be reformatted or overwritten by the PI in Maynooth University.

**What will happen to the results?** The research will be written up and presented as a doctoral thesis. Plans to disseminate the results of this research include publications in academic journals, open-access accessible formats, and may be presented at National and international conferences. A copy of the research findings will be made available to you upon request.

**What are the possible disadvantages of taking part?** I don't envisage any negative consequences for you in taking part or It is possible that talking about your experience may cause some distress.

**What if there is a problem?** Immediately following the interview, responses will be restated to the participant and adjustments made based on clarifying comments. With this approach, all stories are recorded as the participant confirms is true to their perspective, and ensuring transparency. If you feel the research has not been carried out as described above, or experience any concerns following the interview, you may contact my supervisor Dr. Malcolm MacLachlan, Mac.MacLachlan@mu.ie.

**Any further queries?** If you need any further information, you can contact me: Holly Wescott, +1 206 491 1437, holly.wescott.2019@mumail.ie.

If you agree to take part in the study, please complete and sign the consent form overleaf.

**Thank you for taking the time to read this.**

## Consent Form

I.....agree to participate in Holly Wescott's research study titled Stories of change: Uncovering the process of United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD) programming and disability rights through Bourdieusian case study analysis.

Please tick each statement below:

The purpose and nature of the study has been explained to me verbally & in writing. I've been able to ask questions, which were answered satisfactorily.

I am participating voluntarily.

I give permission for my interview with Holly Wescott to be hand-written on paper.

I understand that I can withdraw from the study, without repercussions, at any time, whether that is before it starts or while I am participating.

I understand that I can withdraw permission to use the data right up to submission of thesis on 31 October 2022.

It has been explained to me how my data will be managed and that I may access it on request.

I understand the limits of confidentiality as described in the information sheet

I understand that my data, in an anonymous format, may be used in further research projects and any subsequent publications if I give permission below:

*Please select from the following permissions:*

I agree to quotation/publication of extracts from my interview

I do not agree to quotation/publication of extracts from my interview

I agree for my data to be used for further research projects

I do not agree for my data to be used for further research projects

I agree for my data, once anonymised, to be retained indefinitely in the IQDA archive

Signed.....

Date.....



Participant Name in block capitals .....

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*I the undersigned have taken the time to fully explain to the above participant the nature and purpose of this study in a manner that they could understand. I have explained the risks involved as well as the possible benefits. I have invited them to ask questions on any aspect of the study that concerned them.*

Signed.....

Date.....

Researcher Name in block capitals .....

*If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at [research.ethics@mu.ie](mailto:research.ethics@mu.ie) or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.*

*For your information the Data Controller for this research project is Maynooth University, Maynooth, Co. Kildare. Maynooth University Data Protection officer is Ann McKeon in Humanity house, room 17, who can be contacted at [ann.mckeon@mu.ie](mailto:ann.mckeon@mu.ie). Maynooth University Data Privacy policies can be found at <https://www.maynoothuniversity.ie/data-protection>.*