Olshanska, Z., J. van Doorn and S.C. van Veen. 2016.
My story, my rights: how individual stories of people with disabilities can
contribute to knowledge development for UNCRPD monitoring.
Knowledge Management for Development Journal 11(2): 43-62
http://journal.km4dev.org/

My story, my rights: how individual stories of people with disabilities can contribute to knowledge development for UNCRPD monitoring

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The Convention on the Rights of Persons with Disabilities (UNCRPD) demands the involvement of persons with disabilities, however, their voice is often excluded from monitoring processes. The project My Story My Rights tested Participatory Narrative Inquiry (PNI) as a method for UNCRPD monitoring in Uganda. Through the project, 197 stories were shared by persons with disabilities from eight districts. Storytellers also completed questionnaires which identified important themes, barriers and actors in their stories, with ‘Education’, ‘Work & Employment’, and ‘Healthcare’ emerging as the most recurrent themes. During four sense-making sessions, 24 storytellers and 56 community members, representing key public institutions, discussed patterns across their stories and brought collective meaning to the three themes. A selection of project results was shared with the UNCRPD Committee in Geneva to support monitoring of UNCRPD implementation. Insights gained through use of PNI was found to add value to UNCRPD monitoring by offering quantitative and qualitative data on barriers and actors important for realizing the rights of persons with disabilities concerning the three themes. The method enabled people with disabilities to participate in monitoring by sharing their stories with their communities and developing knowledge about disability rights in Uganda.

Keywords: United Nations Convention on the Rights of Persons with Disabilities; Participatory Narrative Inquiry; disabilities; stories; local knowledge; monitoring; Uganda

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) marked an important shift towards understanding disability as a human rights issue (Schulze 2010; Stein & Lord 2010). Currently, 167 State Parties have ratified the Convention. Uganda was among the first 46 countries to ratify the Convention in 2008 (UN OHCHR 2016). The Convention recognises disability as a consequence of interaction between individuals and their environment (Stein 2007; Stein & Lord 2010), and requires states and all sectors of society to create conditions that allow for meaningful participation of people with disabilities in all aspects of society (UN, 2006). Article 33 of the UNCRPD requires States Parties to set up frameworks to promote, protect and monitor its implementation of the Convention with participation from civil society, including Disabled Peoples Organisations (DPOs) and particularly persons with disabilities (UN 2006).

This participatory approach to monitoring the UNCRPD implementation reflects one of the main principles of the Convention, namely that people with disabilities should participate in all decisions that influence them (Stein & Lord 2010). Rather than excluding persons with disabilities, participatory monitoring invites them to be active in contributing and analysing data as and alongside researchers. This process enables persons with disabilities to share their views, articulate their needs and expectations, raise awareness of the issues at stake, and contribute to the identification of collective priorities (Cocks & Cockram 1995). In this regard, participatory monitoring offers an opportunity for sharing and negotiating knowledge among different stakeholders in UNCRPD implementation, making the process of knowledge co-creation more conscious and flexible (Cousins & Whitmore 1997).

Despite several initiatives to integrate the voices of persons with disabilities into UNCRPD monitoring, such as ‘Disability Rights Promotion International’ and ‘The International Disability Rights Monitor Project’(Lawson, Anna; Priestley 2009), it remains an ongoing challenge to fully involve persons with disabilities in the monitoring process due to the lack of capacity among Disabled People’s Organisations (DPOs) in monitoring, and limited financial resources (Samson 2015). Recognising this, Light for the World Netherlands, Action on Disability and Development (ADD), and National Union of Disabled Persons of Uganda (NUDIPU) initiated the My Story My Rights (MSMR) project to test the methodology of Participative Narrative Inquiry (PNI) for monitoring disability inclusion. The project aimed to include the voices of persons with disabilities in Uganda as supportive information to the shadow report submitted by Ugandan civil society organisations (CSOs) in 2013 (NUDIPU 2013). The results of the project, along with information from many CSOs and DPOs, were shared with the UNCRPD Committee in its review of the shadow report in April 2016.

In this paper we first reflect the importance of participatory monitoring of human rights and introduce methodologies that place a strong emphasis on participation and knowledge co-creation. Then, we explain the theoretical foundation and process of PNI, and why this method was chosen in the project. In the methodology, we explain how PNI was put into practice in the MSMR project in Uganda. In the results, we provide insight into the specific outcomes of the project, showing how the process of story-sharing and sense-making discussions generated complementary quantitative and qualitative data. By reflecting on knowledge created by participants and the methods used the MSMR project in the discussion section, we aim to show the possible value of PNI in the UNCRPD monitoring process.

Background on participatory human rights' monitoring

The purpose of the United Nations (UN) and its human rights treaties is to 'promote and encourage respect for human rights and fundamental freedoms for all' (UN 1948). To ensure that states adhere to their responsibilities as enshrined in these treaties, it is essential to monitor progress on the realisation of human rights. With regard to UNCRPD monitoring, progress reports are periodically submitted by governments and civil society to the UNCRPD Committee (UN 2006). The Committee uses these reports to review implementation of UNCRPD in countries that have ratified the Convention, and to make recommendations to governments for areas in which improvement is required. While the government reports are usually focused on law and policies, the so-called shadow reports from civil society aim to provide insights into discrepancies between law, policies and practice (McCallum 2010). Governments and CSOs use various strategies for monitoring UNCRPD implementation. According to Landman (2004), human rights can be measured against three outcomes: principles, policy, and practice. The latter in particular is seen as a decisive outcome, as it examines whether human rights are actually realised on the ground (Pinto 2015). Assessing this complex and variable outcome in relation to the UNCRPD necessarily requires participation by persons with disabilities, because their experiences are a way to assess the efficacy and impact of laws and policies (Samson 2015).

Various participatory research methodologies with a strong emphasis on participation and knowledge co-creation could help to include to document the experiences of persons with disabilities in exercising their human rights. Some utilise stories, such as Most Significant Change (MSC) (Dart & Davies 2003; Davies & Dart 2005), Learning Histories (LH) (Kleiner & Roth 1996), and Participatory Narrative Inquiry (PNI) (Kurtz 2014). These methodologies, presented in Table 1, all take into account the experiences of people at the grassroots level, with personal stories being at the centre of research. In MSC and PNI, stories are directly told by respondents and used in their raw form (Dart & Davies 2003; Kurtz 2014), while in LH stories are compiled by researchers from multiple individual interviews from which general themes emerge (Kleiner & Roth 1996).

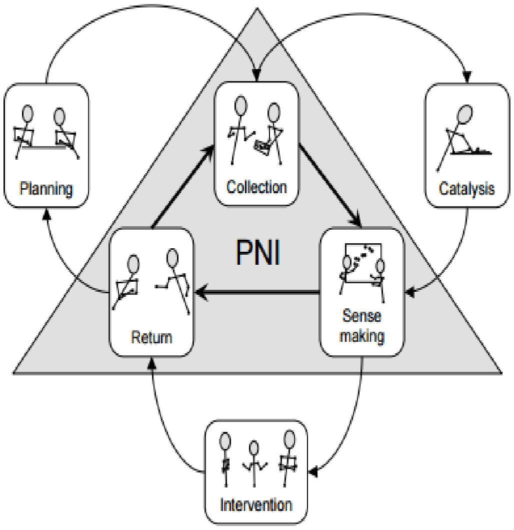
Table 1: Participatory research methods utilising stories

Name	Purpose	Process in summary	Characteristics
Most Significant Change (MSC)	Program monitoring and evaluation	- Researchers gather stories on significant change at beneficiary level. - Researchers organise stories in hierarchical structures, based on qualitative analysis of the significance of the changes depicted. - Storytellers are surveyed about aspects of the program that relate to most significant changes. - Findings of the MSC process are used to evaluate program impact/outcomes and to determine funding priorities.	MSC focuses on personal experiences of beneficiaries using primarily **qualitative** data from stories to **prioritise aspects** of a program that bring about most significant change. Next to the strong emphasis on stories (qualitative data), beneficiaries are also surveyed (quantitative data) on important program aspects. The beneficiaries participate by sharing their stories and interpreting their relation to important programme aspects.
Learning Histories (LH)	Organisational change	- Researchers construct a story of a change process based on interviews with different stakeholders. - Researchers qualitatively analyse themes and plots in the stories, for insight into the change process. - All stakeholders provide their reflections on this analysis. - Optionally, a wider public can learn from the stories and provide reflections related to their context.	LH focuses on the construction of **multi actor stories**, based on interviews and **qualitative** analysis. A story is constructed based on participants' interview responses. Participants provide their **reflections** on the themes and plots of the constructed story, contributing to its refinement. LH uses the constructed stories for **learning and reflection** within an organisation or in a wider context.
Participatory Narrative Inquiry (PNI)	Community and Organisations	- Researchers develop a qualitative question to ask beneficiaries to tell their stories and a quantitative questionnaire that can help to interpret stories in accordance to project aim - Researchers gather stories on individual experiences at beneficiary level. - For each story, the storyteller also answers quantitative questions about their story. - During catalysis the researchers analyse the patterns in the stories in accordance to the quantitative data. - During sense-making sessions, storytellers and key stakeholders provide meaning to patterns identified in the stories. - Findings of sense-making sessions are shared within the organisation/s or with the broader community.	PNI focuses on gathering and working with personal **stories** to generate both **quantitative and qualitative** data about complex issues. Mixed method analysis is used to discover patterns in the gathered stories. Storytellers and interested others then interpret these patterns and negotiate shared meaning of the stories. PNI places a strong emphasis on participation as a **method of knowledge co-creation**. Specifically, the sense-making stage allows involvement of diverse local actors. The **return stage** brings back the results to the organisation, community and/or wider public.

The methods differ in how stories are analysed and applied to inform program evaluation, organisational change or community development. All three tools use qualitative analysis to do justice to the rich data that stories provide. In addition, PNI and MSC include quantitative analysis, though differently conducted. While MSC considers quantification as one of the last steps to complement the qualitative information (Davies & Dart 2005), PNI uses quantitative data to regulate qualitative analysis (Kurtz 2013). Furthermore, the approaches differ in how participation is managed. All ensure participation of stakeholders in the analysis process. MSC and LH focus on multi-level participation, wherein all types of stakeholders can participate in sharing and utilising insights gleaned from stories. For example, with MSC, program managers can use the information from stories to determine future priorities. PNI, on the other hand, ensures interpretation and analysing of the stories by storytellers themselves by asking quantitative questions about the stories and through a process called ‘sense-making’ that also include their close communities. Kurtz (2013) emphasises the importance of analysis of stories by storytellers and key stakeholders to ensure that interpretation and meaning are based on their experience.

Given that PNI methodology extends the participation of storytellers from sharing their stories to also interpreting and negotiating their meaning, we selected it as our participatory monitoring tool, to explore experiences of persons with disabilities regarding UNCRPD implementation in Uganda.

Figure 1: *Participatory Narrative Inquiry consists of six phases (Source: Kurtz 2014: 89)*



Methodology

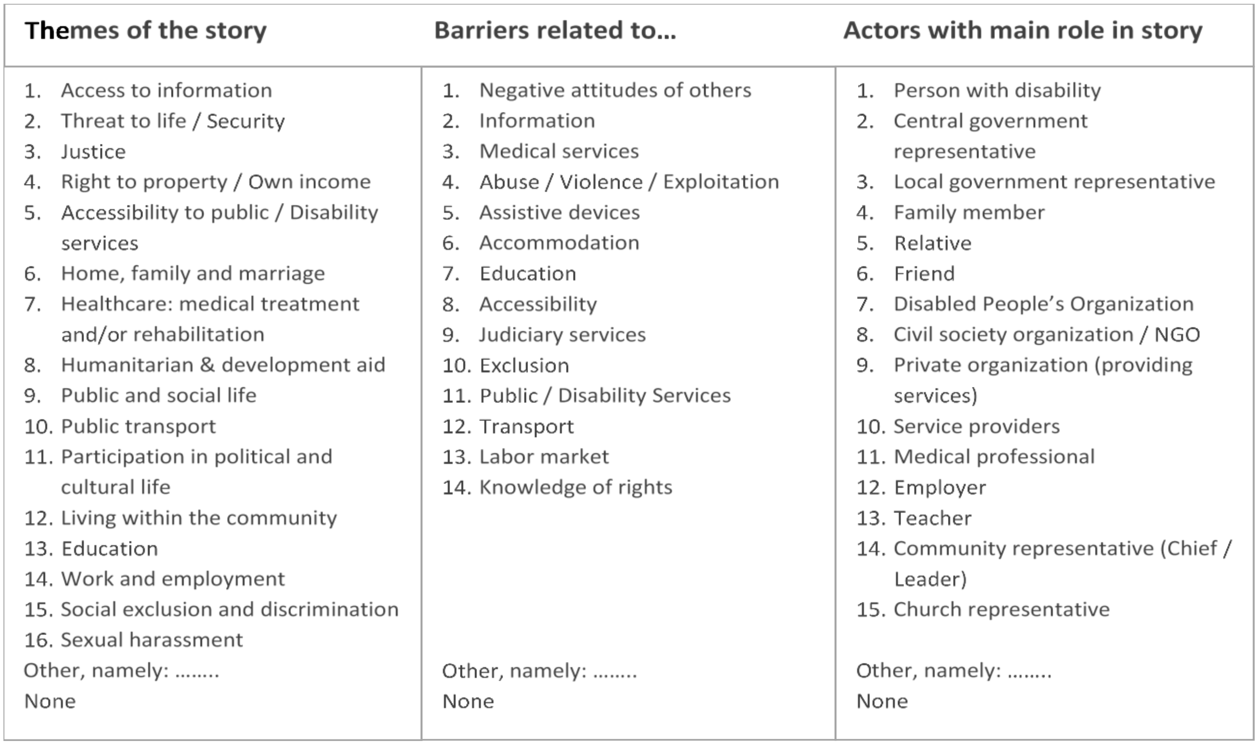
Light for the World Netherlands together with ADD International and NUDIPU initiated the pilot project My Story My Rights (MSMR) in February 2015, to test the value of PNI to complement existing UNCRPD monitoring mechanisms. Uganda was chosen as location for the study as it was among the first countries to ratify the UNCRPD and its Optional Protocol in 2008, and thus has the necessary legal framework for UNCRPD monitoring. Furthermore, Uganda has a network of established DPOs which play a key role in evaluating and monitoring services for persons with disabilities in that country, and have experience in providing shadow reports (NUDIPU 2013).

The MSMR project was organised according to the six PNI phases: planning; collection; catalysis; sense-making; intervention; and return (see Figure 1). The phases inside the triangle (collection, sense-making, and return) actively involve persons with disabilities and their communities in data collection and analysis. These phases were followed in eight districts in Uganda (Lira, Apac, Kiboga, Hoima, Mbale, Iganga, Mbarara, Wakiso). The phases outside the triangle (planning, catalysis, and intervention) were carried out by the project team, which involved Ugandan and Dutch members with and without disabilities. All phases were carefully documented and discussed with experts in the field of disability rights and monitoring from outside the project.

During *the planning stage* the project team, consisting of six people from ADD, NUDIPU and Light for the World, together with the representatives of eight District Unions (district affiliates of NUDIPU) were trained in the PNI approach. During this training the following prompt was developed to motivate storytellers to share their experiences: *Could you recall a moment of your life in the last 8 years when you experienced any discrimination or abuse in your daily life? Or when you witnessed a positive difference made to you by a person or organisation?* The time period of eight years was chosen as the timeline for the study as ratification of UNCRPD was eight years ago.

In addition to the prompt, the project team developed a questionnaire about the story to facilitate the catalysis process. Filling of this questionnaire by the storytellers was a separate activity, after having shared their stories. Specifically, the questionnaire intended to maximize understanding of the stories in regard to UNCRPD themes and to help produce patterns that could advance sense-making discussions. In the questionnaire sixteen themes were adopted from UNCRPD articles 9-30. Furthermore, fourteen possible barriers to inclusion and fifteen actors (people or organisations involved in the respondents' experiences) were presented in the questionnaire in discussion with representatives from NUDIPU and District Unions who facilitated framing of barriers and actors in regard to the Ugandan context (see Figure 2).

Figure 2: ***The 16 themes, 14 barriers, and 15 actors covered in the questionnaire***



Themes of the story

1. Access to information
2. Threat to life / Security
3. Justice
4. Right to property / Own income
5. Accessibility to public / Disability services
6. Home, family and marriage
7. Healthcare: medical treatment and/or rehabilitation
8. Humanitarian & development aid
9. Public and social life
10. Public transport
11. Participation in political and cultural life
12. Living within the community
13. Education
14. Work and employment
15. Social exclusion and discrimination
16. Sexual harassment

Other, namely: ……..
None

Barriers related to…

1. Negative attitudes of others
2. Information
3. Medical services
4. Abuse / Violence / Exploitation
5. Assistive devices
6. Accommodation
7. Education
8. Accessibility
9. Judiciary services
10. Exclusion
11. Public / Disability Services
12. Transport
13. Labor market
14. Knowledge of rights

Other, namely: ……..
None

Actors with main role in story

1. Person with disability
2. Central government representative
3. Local government representative
4. Family member
5. Relative
6. Friend
7. Disabled People's Organization
8. Civil society organization / NGO
9. Private organization (providing services)
10. Service providers
11. Medical professional
12. Employer
13. Teacher
14. Community representative (Chief / Leader)
15. Church representative

Other, namely: ……..
None

Given this research aimed to provide input for shadow reporting on the UNCRPD, the focus was on barriers and difference made by people or organizations. However, we may question this focus since it does not pick up facilitators of change easily.

During *the collection stage* the team and District Union representatives mobilized persons with disabilities to share their stories. Sign-language interpreters were arranged. 197 persons with disabilities from eight districts shared their stories in group interviews. Stories were shared in two smaller groups of four to eight people (ten to sixteen people in total) per district (Kurtz 2014). After story sharing in the small groups, storytellers were asked to fill in the questionnaire identifying the main themes, barriers and actors in their stories. Before the interviews, consent was sought for use of the participants' stories for UNCRPD monitoring and advocacy/awareness-raising purposes. The respondents' stories were recorded, transcribed, and where necessary translated into English. Together with the questionnaires they were uploaded into the database which was used to generate input for the sense-making sessions.

This data informed the *catalysis stage* during which the transcripts of stories and data from questionnaires (on demographic characteristics of respondents, prioritised themes, barriers and actors) was uploaded and visualised with the help of Tableau Reader software. The stories provided the researchers with in-depth insight in how barriers were experienced in practice and the role different actors played herein. The questionnaire was used to solidify and represent all patterns across stories, while the story transcripts provided in-depth meaning to the identified patterns. For example, the questionnaire offered insight into what themes were prioritized by male and female storytellers and which barriers were most mentioned in stories with a certain theme.

These findings were not considered conclusive evidence, but were used to facilitate sense-making discussions as per the PNI methodology (Kurtz 2014). During *the sense-making stage,* 24 storytellers and 56 community members representing key public institutions (specifically, teachers, nurses, legal officers, religious leaders, District Union chairs, community development officers) came together to discuss the preliminary findings of collection and catalysis stage. In total, four sense-making sessions were organized. For each session, 5-6 storytellers and 14 community members from two geographically close districts were mobilized. Participants reflected on findings and trends identified in the stories during the catalysis stage of the study and analysed the transcripts of related stories, providing their own interpretation of situations experienced by persons with disabilities. In this sense, the result of catalysis formed the basis for sense-making dialogues between both persons with disabilities (storytellers) and members of their community about their understanding of story patterns, specifically the relation between themes, barriers and actors, and the meaning persons with disabilities attribute to them.

The intervention stage was not specifically planned, but was integrated into the sense-making and return stage as an awareness-raising dialogue about disability rights. *The return stage* was organized as a final workshop. 24 storytellers and 20 community members (from different districts) who participated in the sensemaking sessions, and wider public including representatives of local NGOs and CSOs, local government representatives, the equal opportunity commissioner, Ugandan parliament representative and local media were invited to reflect on the overall results of the MSMR project. The purpose of return stage was to inform a broader public about the experiences on realization of the rights of persons with disabilities in the context of Uganda. Furthermore, a selection of results was later shared with the UNCRPD Committee in Geneva in the form of a report.

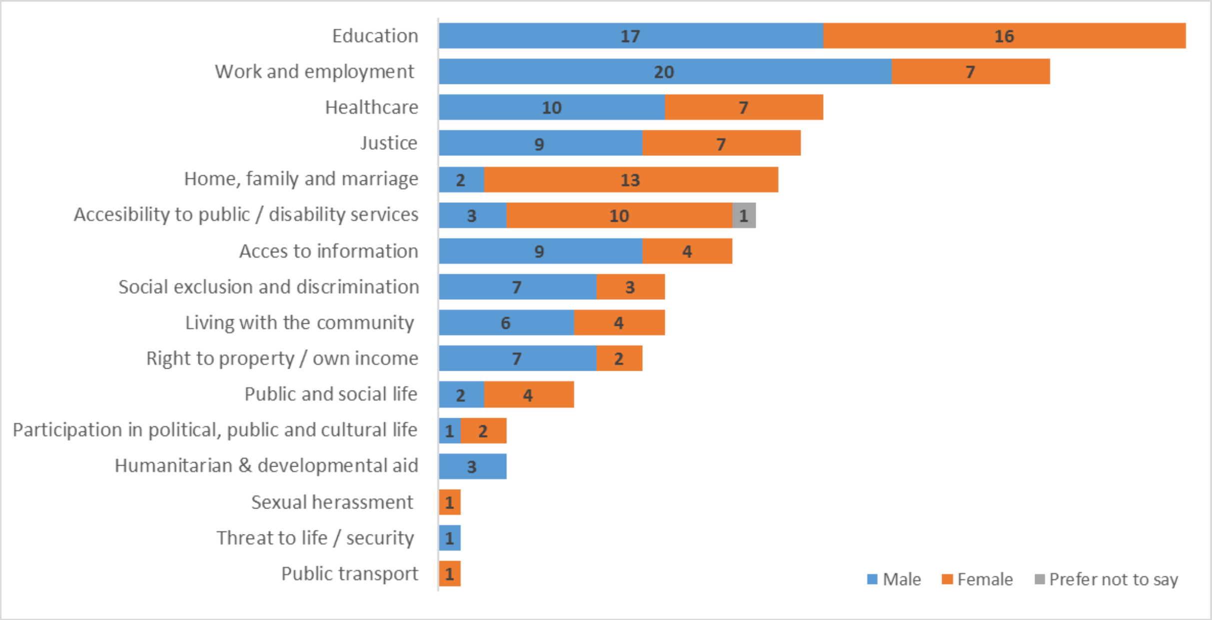
Results

In accordance with the PNI methodology, results of the MSMR project were generated through the processes of catalysis and sense-making. Catalysis helped the project team discover patterns across stories that were used as ‘food for thought’ in the sense-making process (Kurtz 2014). The participants of sense-making sessions (both storytellers and community members) discussed the patterns and raw stories in groups sharing their understanding of catalytic results. These interpretations constituted the conclusive evidence revealing the nature of experienced barriers and actors mentioned in regard to certain themes. For this reason, both catalysis and sense-making provided context and relevance for understanding the MSMR results.

The catalysis revealed the scope of the data that was collected: 197 stories from persons with disabilities from eight districts of Uganda (19-25 stories per district), with a roughly equal participation of male (55%) and female (45%) storytellers. Most storytellers reported physical (45%) and sensory (visual and hearing 35%) disability types, with other types (including albinism and intellectual disability) under-represented in the sample (around 20%).

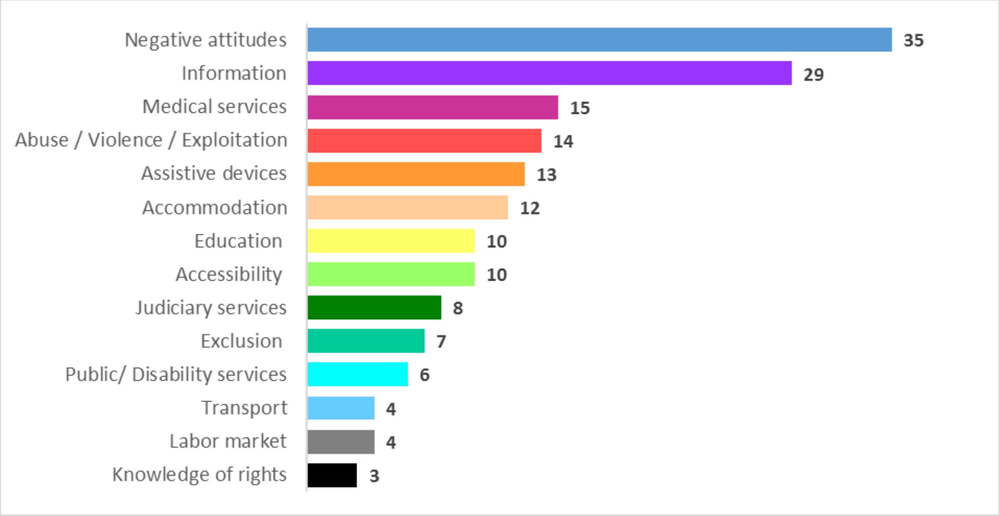
The catalysis also provided information on themes, barriers and actors that storytellers identified as the most important (See Figure 3). The gender lens made apparent that after ‘Education’, female participants prioritised ‘Home, Family and Marriage’ and ‘Accessibility to Public/Disability Services’, while men highlighted ‘Work & Employment’.

Figure 3: Histogram showing the prioritisation of the UNCRPD themes disaggregated by sex



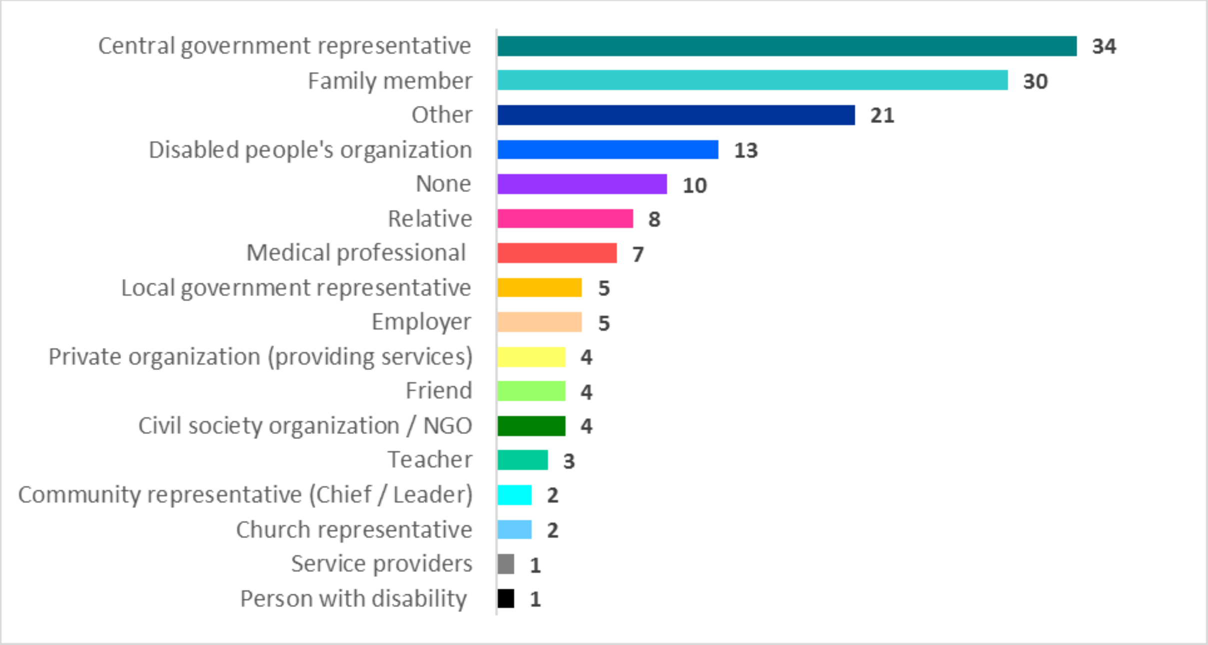
In addition to the themes, catalysis also revealed which barriers and actors appeared to be most significant in shaping the experience of persons with disabilities in Uganda in relation to specific themes (see Figure 4). ‘Negative attitudes of others’ (mentioned in 35 questionnaires), and ‘Lack of access to information’ (mentioned in 29 questionnaires) were indicated most frequently as barriers across the full set of stories.

Figure 4: Histogram of barriers



With regard to the actors, catalytic data showed that Government including ‘Central government representatives’ and ‘Local government representatives’ (mentioned in 34 and 5 questionnaires respectively) was considered most significant (see Figure 5), followed by ‘Family Member’ (mentioned in 30 questionnaires).

Figure 5: Histogram of actors



The preliminary findings from catalysis were discussed with invited storytellers and their community members during sense-making sessions. The story patterns did not raise questions among participants but rather acknowledgment, resulting in sharing of individual experiences among storytellers and their community members. Besides, participants showed a great sensitivity for gender when discussing the nature of barriers experienced by men and women with disabilities. During the sense-making session participants agreed to focus on the three themes ('Education', 'Work & Employment', 'Healthcare'), barriers and actors that come across a majority of stories. They explained this choice by the wish to concentrate on the issues that are most pressing in their communities and that they all, both storytellers and community members, can relate to.

Education

'Education' received the most attention by participants at sense-making sessions, which also reflects the high number of stories that related to that theme (n=33). The vast majority of the storytellers (n=26) were young people, aged between 11 and 35 years, while the remaining (n=7) were aged 36 years and older.

The stories bring into focus significant barriers to education faced by young persons with disabilities in Uganda, the most frequent of which is 'Negative attitudes of others'. The following story quotes show how this barrier is experienced:

- *…I failed to concentrate because of stereotypes that were surrounding me at school.*
- *…I can't walk properly. This interfered with my early education. When I was at school, the children used to abuse me and laugh at me.*
- *I was always regarded as a stupid person because of my physical disability.*

During sense-making sessions, both storytellers and community members agreed that the most important barrier to education for young persons with disabilities are negative attitudes of their teachers and peers at school who very often use 'discriminating' and 'stigmatising' language when communicating to or about a child with a disability. Such experiences cause many children with a disability drop out of school or never enrol, even though the right to pursue education is set out in the UNCRPD (UN 2006: Article 24).

The other frequently mentioned barriers in the stories include lack of accessible formats, lack of accessible learning environment, and lack of special needs teachers. These barriers were also emphasised by participants at sense-making sessions. In most cases participants mentioned them as secondary barriers after 'Negative attitudes of others'. The following story quotes show how these barriers are experienced:

- *…I was born deaf. I went to school for three years but there were no sign language interpreters … I never understood anything for these three years because I can't hear and I can't talk so I dropped out of school...*
- *I have a low vision problem and this is causing me to lose interest in studies. I have to wait for other students to write notes for me…*

The stories also bring into focus the role of different actors in enabling or inhibiting access to education by persons with disabilities, the most significant of which was 'Family member', as exemplified by the following story quote:

- *My father refused taking me to school saying that I am deaf and have a physical disability…*

During sense-making sessions, some storytellers noted that often a family member motivated them to pursue education. Others explained that in some cases it is the family that prevents access by not believing in the person's capacity to study. The participants also highlighted the responsibility of 'Government' to enable the implementation of an inclusive education system (UN 2006). Specifically, they mentioned the role of government in sensitizing teachers on disability through offering disability awareness sessions at schools with the example of good practices and differences made to individuals' lives.

Work & Employment

'Work and Employment' was the focus of great attention at sense-making sessions, which also reflects the high number of stories that related to that theme (n=27). Half of these came from storytellers of prime working age, between 35-45 years.

'Negative attitudes of others' was once again considered the most significant barrier to work and employment by persons with disabilities in Uganda, in the stories that related to this theme. Storytellers said that they are often perceived as 'incapable of doing a job', as the following story quotes reveal:

- *...3 years ago I was looking for work and I came across a job advert. I went for my interview… as I was walking out of the room one of the panel members asked what had happened to me…I told him that I had a physical disability. He asked why I wasted their time. ....He said that I cannot be an engineer because I'm disabled.*
- *One day I went to search for a job…It was about teaching. When I got there, people told me that they could not give me a job because of my disability.*

During sense-making sessions, participants agreed that ‘Negative attitudes of others’ was a significant barrier to work and employment, typically experienced in the form of abuse or insult which is a widespread practice among employers who do not consider persons with disabilities ‘productive’ and tend to pay them lower wages than their ‘able-bodied’ colleagues.

Another barrier identified by storytellers was ‘Lack of accessibility to the labour market’, often linked to ‘Lack of access to information’. Participants at sense-making sessions discussed how persons with disabilities do not just encounter physical barriers in accessing work places, but they are often also excluded due to non-inclusive job application procedures (e.g. non accessible application forms and accommodation provided during the interview and selection process).

Regarding the actors, sense-making participants concurred with catalytic results recognizing the role of ‘Government’ in the implementation of inclusive employment practices and providing persons with disabilities with the necessary services and devices that would enable them to work. Participants emphasised the importance of countering negative perceptions of disability at workforce through the enactment of inclusive laws in Uganda (The Persons with Disabilities Act, 2006; The Equal Opportunity Act, 2006, the Employment Act (No. 6), 2006; UN 2006: Article 25). In their view, lack of enforcement and political support from government officials leaves the issue of disability out of focus of employers. Besides, participants emphasized the importance of local governments in involving disabled peoples organizations for sensitizing employers on disability and inclusive practices.

Healthcare

‘Healthcare’ also received considerable attention at sense-making sessions, which is indicative of the high number of stories that related to this theme. Half these stories came from older respondents aged between 45-65 years.

When elaborating on barriers to healthcare, storytellers referred mainly to ‘Lack of access to medical services’, and ‘Negative attitudes of others’. In sense-making sessions, participants explained that persons with disabilities are excluded from the same health services as other members of the community due the physical inaccessibility of the medical environment (no ramps, high beds, no wheelchairs in the hospitals etc.), as well as lack of training by health professionals who do not know how to treat a person with a disability, and very often resort to stereotypical behaviour as illustrated in the story quote below:

- *I approached a health facility for an HIV test and counselling only to be rejected by the health worker on the grounds that I was visually impaired and wondered why I would seek for such a service…*

Participants at sense-making sessions emphasised the particular difficulties faced by people with intellectual disabilities who tend to experience most stereotyping, being associated with witchcraft in Uganda. As a result, persons with intellectual disabilities often conceal their disability to prevent denial of care as exemplified by the following story quote:

- *I became epileptic at the age of three years… After my father died I decided to live with my brothers. They chased me away saying that I am a witch and I would bewitch their children.*
- *I have mental illness. When my mother takes me to the doctor, she tells them that I was bitten by an insect. Otherwise they won't treat me.*

In regard to actors that influence healthcare experiences of persons with disabilities, the views of sense-making participants corresponded significantly with the results of catalysis: 'Family members' and 'Medical workers' are seen as most important. In many stories, family members are portrayed as the one(s) who initially decide whether a child with a disability is given appropriate treatment and rehabilitation support:

- *I was young when my eye got sick… My father took me to the hospital...Unfortunately when the doctors explain to him the type of treatment, he got scared and declined.*

Sense-making participants explained that the family often decides not to invest in the necessary treatment, as medical costs are too high and families have limited resources or they do not trust their effectiveness. Concerning the 'Medical workers', participants reasoned that their negative attitudes frequently result from the lack of awareness or enforcement of existing regulations that require medical activities to be accessible to people with disabilities. In this sense, participants again emphasized the role of 'Government' in the sensitisation of health personnel as articulated in the UNCRPD (UN 2006: Article 25).

Sense-making discussions of catalytic results elucidated more light on story patterns in relation to the themes 'Education', 'Work & Employment' and 'Healthcare'. In most cases, participants agreed that it is not the lack of inclusive policies and regulations but 'negative attitudes of others' that provoked intolerant behaviour towards persons with disabilities within institutions and families. Regarding the actors, sense-making participants recognized that they may exercise both positive (helping to overcome the barrier) and/or negative (creating a barrier) influence on experiences of persons with disabilities. Besides, the discussions brought to the fore the interrelation in the position of actors: the 'negative attitudes' of teachers, employers and medical workers were linked to the inability of 'Government' to enforce inclusive policies and to sensitize the public institutions on disability inclusion.

Discussion

The findings of the MSMR project suggest that PNI offers a sound framework for collecting and interpreting rich information and data about the human rights situation of persons with disabilities in Uganda, of relevance to inform UNCDRP monitoring. PNI combines on two types of complementary results: rich qualitative stories of individual testimonies and quantitative data from the questionnaire relates these testimonies to project aims (in this case themes, barriers and actors related to the UNCRPD). Both types of data were shown to have value for the UNCRPD monitoring process in Uganda. On the one hand, quantitative results provided evidence on the frequency of problems that people with disabilities experience. Although one could question if the focus on barriers steers the research towards negative results on disability rights, the openness in story telling as a first step gave room for any positive or negative experience related to disability rights. On the other hand, qualitative data offered a better understanding of the 'how and why' and herein possible solutions related to the implementation of disability rights came forward.

A second value of PNI is its participatory character, as it offers space for persons with disabilities to engage in the monitoring process during which they are both storytellers and interpreters of the results. Based on the experience of UNCRPD monitoring in Zambia, Birtha (2013) defines full participation according to the following principles: 1) early-stage involvement; 2) involvement of a broad range of people on the ground; 3) awareness-raising; 4) continuous evaluation of the monitoring process; and 4) provision of evidence-based data for influencing policy-makers. In accordance with this perspective and the requirement of the UNCRPD of full participation of persons with disabilities and their representative organizations in the monitoring process as articulated in Article 33 (3) (UN, 2006), the PNI methodology provided a framework to support the full participation of persons with disabilities in the process of monitoring, although we could question whether the first principle was met by the MSMR project since the research took place eight years after the ratification of the UNCRPD in Uganda.

However, the participative approach of PNI not only contributed to the generation of experience or practice-based knowledge to complement formal monitoring methods, but also encouraged people with disabilities to speak up for themselves, turning them from objects of study to the experts of their own situation (Samson 2015). During the MSMR project, emphasis was placed on including a broad range of marginalised groups like women with disabilities, and people with albinism and intellectual disabilities. Even though the percentage of the latter two groups was lower than expected compared to persons with physical and sensory disabilities, their participation and presence in storytelling and sense-making assured wider resonance of the issues discussed.

Sense-making sessions allowed persons with disabilities to engage in a dialogue with other community members about their human rights experience. These sessions offered a platform for sharing of different views on important themes, barriers and actors in relation to disability rights, which contributed to a better understanding of complex issues. The dialogue promoted and enhanced the participants' knowledge about- and respect for disability rights. Similar experiences were shared by participants in the final workshop when the invited representatives of local CSOs reflected on their first exposure to disability rights work. In this sense, monitoring UNCRPD implementation by using the PNI method provided space for diverse community members to reach new understandings of disability experiences, thereby contributing to the process of knowledge co-creation about issues faced by people with disabilities in Uganda.

A summarised report of the three most pressing issues identified by the MSMR project, illustrated with the voices of persons with disabilities in story quotes, was shared by the NUDIPU delegation with the UNCRPD Committee during the last review meeting in Geneva in April 2016, to complement the 'expert'-based information from the shadow report (submitted in 2013). The concluding recommendations of the UNCRPD Committee showed that the project data alongside other evidence presented by Ugandan civil society was considered as legitimate information to inform the Committee's recommendations. Mirroring our core findings, the Committee called upon the Government of Uganda to improve the access of persons with disabilities to the education system, labour market and health institutions – not only by reforming these institutions, but also by eliminating any discrimination and negative stereotypes about disability (UN 2016).

Limitations

In the process of testing PNI for UNCRPD monitoring in Uganda, we encountered three distinct challenges. The first challenge relates to the influence of using group interviews and questionnaires to the free-speaking storytellers. Using group interviews could raise questions about how private and freely the storytellers felt to share their story and whether they influenced each other. However, sharing stories in a group can help to raise self-esteem of storytellers, stimulating group awareness and problem solving. To ensure this, good facilitation and some time for building up trust between the members the group is important. The use of structured questionnaires may hamper doing justice to the richness of the stories. To counter this challenge as much as possible, the storytellers were asked to fill in the questionnaire after they shared their stories and the stories were transcribed and analysed as well.

The second challenge relates to the representation of persons with disabilities of all age groups and types of disability. It was a challenge to ensure full participation of children with disabilities and adults with intellectual disabilities. The question is not whether PNI allows all persons with disabilities to participate, regardless of age or disability types, but whether methods of data collection and participatory analysis used in the PNI framework are inclusive for persons who use certain alternative forms of communication (Booth & Booth 1996). For instance, MSMR used oral storytelling in small groups stimulated by a prompting question for story collection. To ensure full participation of children with disabilities and people with intellectual disabilities, other methods could be applied. For example, the 'photo-interviewing' approach, when photos are used as a teaser to encourage respondents to talk, could increase the interest and capacity of children with disabilities participating in a study (Cappello 2005). Another option may be assessing experiences with support of close relatives or friends, but as Ware (2004) argues, it is not the same as being able to express one's own views. Therefore, interviewing a proxy about a person with an intellectual disability should be kept under constant review.

The third challenge concerns the informed consent from vulnerable groups as persons with intellectual disabilities and children with disabilities. In order for consent to be informed, participants must be able to grasp the information they have been given and to consider whether they would like to participate. This refers to capacity to make decisions and understand consequences of those decisions (Curran & Hollins 1994, cited in Dunn et al. 2006). For example, parents are asked for consent in the case of minors, but the issue remains problematic due to the unequal power between adults and children, who may find it difficult to tell an adult researcher whether or not they want to participate in a study. Furthermore, participants, particularly in the case of vulnerable groups, may feel obliged to consent due to pressure from researchers, family or peers. Even though some researchers advise documenting individual informed consent using alternative methods like photography, graphics or video (e.g. Andre-Barron et al. 2008), there is no empirical evidence on the implications of using such methods for obtaining consent for specific disability populations.

Conclusions

Despite some challenges, the MSMR project demonstrates how the participatory, story-based PNI method can engage persons with disabilities as monitors of their human rights experience, which in turn can be a valuable input to the process of UNCRPD monitoring. The project findings offered integral sources of information on experiences of persons with disability in Uganda, in which qualitative stories gave insight into individual human rights experiences and quantitative data from questionnaires supported the identification of patterns in experiences. Moreover, PNI sense-making sessions facilitated a process of knowledge co-creation allowing participants to collectively reflect on stories and negotiate understanding that is relevant for diverse community members.

By considering the findings of the project, the UNCRPD Committee was able to learn about the experience of persons with disabilities on the ground, and reflect on the efficacy of Ugandan laws and policies to realise disability rights in the areas of ‘Education’, ‘Work and Employment’ and ‘Healthcare’. The PNI methodology offered a possibility to practise and learn about new technique for supporting full participation of persons with disabilities in monitoring their rights.

Acknowledgements

We would like to recognise the contribution of StoryConnect to the MSMR project: from provision of training on PNI to offering technical assistance in setting up and managing the catalysis process and story database. We also acknowledge the valuable feedback provided by Florence Ndagire (ADD International) and Judith Baart (Light for the World Netherlands) on an earlier version of this paper. Finally, we are indebted to all persons with disabilities who agreed to share their stories in the MSMR project and enabled the project team to test PNI methodology.

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