

The Human Rights-Based Approach to Disability in Uganda: Case Study on the General Assemblies of DPOs and the Right to Self-Determination

By Hisayo Katsui

hisayo.katsui@helsinki.fi

Introduction

The human rights-based approach (HRBA) has increasingly been promoted especially with the United Nations (UN) Convention entering into force in May 2008. In theory, the approach has several positive significances to disability in development (Katsui & Kumpuvuori, 2008). This paper focuses on how the approach is operationalised in practice with the case study on the General Assemblies of organisations of persons with disabilities (DPOs) in Uganda. The United Nations claim that dignity, self-determination, equality and solidarity are the four most important values of human rights in the context of disability (OHCHR, 1996-2003). These values are investigated in the Ugandan practices with the special focus on the right to self-determination. Thus, the paper tries to elaborate how such a normative approach is implemented in Uganda in practice. This is part of a bigger research project entitled, “Human Rights-Based Approach to Disability in Development: Interplay of Disability-Sensitive Development Cooperation and National Policy in Uganda, funded between 2007-2010.

Fieldworks were conducted between January-February and December in 2008 in Uganda for interviewing stakeholders of development cooperation activities on disability, including the General Assemblies (GAs) of two DPOs, namely National Union of Disabled Persons of Uganda (NUDIPU) and Uganda National Association of the Deaf (UNAD). Participatory research approach (Katsui & Koistinen, 2008) has been applied to try to make the research process and findings relevant to the Ugandan disability movement as well as to alleviate the power gap between the researcher and the “research participants.” The previous version of this paper was delivered to the Ugandan stakeholders for their reviews and comments prior to the conference presentation¹.

This particular paper focuses on the right to self-determination in the exercise of the GAs of two DPOs in Uganda. Article 29 of the Convention is deeply related to the case study.

Article 29: Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

(a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely

¹ The chairperson of UNAD kindly took so many hours to review the drafts of this paper. He appreciated the description of the NUDIPU GA of the first draft of this paper as based on truth, while was not satisfied with some aspects of the UNAD GA. Several changes were made to the first and second drafts of this paper after his inputs. However, others were left as they were due to the different perspectives between us. The disagreed parts are mentioned in the footnotes in the following text.

chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:

(i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;

(ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;

(iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

(b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

(i) Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;

(ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

The GAs were held in the context of DPO activities and yet similar importance can be addressed through this Article, such as self-determination, right to vote and participation in general. The operationalisations of these, however, are challenging as will be observed below.

The paper first introduces the event of the International Day of Persons with Disabilities (IDD) as a prologue which took place a few days before the two GAs. Secondly, the GAs are introduced with the special attention to ambiguous aspects and incidents of the operationalisation of the HRBA. Subsequently, the strengths of the approach are reviewed, after which the concluding chapter provides implications to better operationalise the HRBA by reflecting on the lessons learned from the case study. The findings and arguments of the paper are largely based on the first hand data collected during and after the conducted fieldworks and my own observation with a special focus on the perspective of deaf women. “Deaf women” are highly heterogeneous. However, their experiences in the following reveal very interesting insights. That is to say, other interpretations of the events from other perspectives are possible.

International Day of Persons with Disabilities (IDD)

IDD was established by the World Programme of Action concerning Disabled Persons, adopted by the United Nations General Assembly in 1982. Since then, 3rd of December has been celebrated for increasing awareness on human rights of persons with disabilities around the world.

IDD event in Uganda is held in different regions every year. In 2008, it was organised in the West Region at Mbarara which is the hometown of the current President. I arrived there with a DPO staffs on the previous night. Various accommodations were

filled with persons with disabilities around the city that night. On the streets, the DPO staffs who travelled with me hugged many colleagues as we walked. There was a lot of excitement in the air for the big event to come.

In the morning of the 3rd of December, we first marched through the downtown with banners. Many DPOs prepared their own T-shirts with their slogans, such as “Convention on the rights of PWDs: dignity and justice for all,” “Education for all: are deaf benefiting, too?” and “Bringing epilepsy in Uganda out of the shadows.” In addition to DPOs, pupils of the local schools for children with disabilities joined the march. People from different organisations mixed up in a short while, and we all marched with a lot of joy. The road was occupied by the crowd of persons and children with disabilities, while people on the streets stopped and learned to know what this day is about. Then, we gathered in a field to celebrate the Day with performances of different groups of persons and children with disabilities with the presence of the honourable guests such as the Minister of Gender, Labour and Social Development, the Third Prime Minister and Minister for Information and guidance who represented the President. The President was also invited but did not show up this year. By this time, the number of people increased to around 1,500. Various representatives of persons with disabilities made speeches. Other than deaf people who needed to be near the sign language interpreters, people sat according to the regions where they were from. The differences of impairments were not visible. Harmony dominated for promoting the “same cause” of human rights of persons with disabilities.

In the socialising event in the evening, people with various impairments gathered in one garden and enjoyed pieces of grilled bull meat donated by the Member of Parliament representing persons with disabilities in the West Region. This was the only food served during the Day: this was the only food many ate for the whole day. Many slept over night in the venue without having money for accommodations.

The event was broadcast on one of the major national television channels, Uganda Broadcasting Corporation, for one whole minute in the evening news on the next day. “Persons with disabilities” were represented as a harmonious group. This image, however, is revealed to be misleading.

Case Study on the General Assemblies of Ugandan DPOs

A few days after the IDD event, the GA of UNAD took place, which was followed by the GA of NUDIPU. These GAs as well as almost all other activities of DPOs are funded by Northern donors, namely Northern DPOs. The GAs of DPOs are held every five years to exercise the delegates’ right to vote and to decide own representatives as well as to receive activity and financial reports and to amend the Constitutions if necessary. Based on the discussions, delegates can vote for new leaders for steering their organisations for the forthcoming five years. The GAs are, therefore, the paramount examples of the operationalisation of the human rights-based approach to disability in Uganda: the goal is to decide their own representatives, and the means is fair and democratic voting. Self-determination is the key word. In the end of the GAs, the guest of honours in the two GAs similarly congratulated the delegates “for exercising democratic right.” In the process of operationalisation, however, many actions turned out to be ambiguous and sometimes even clearly undemocratic

according to my observation focusing particularly on the rights of deaf women. This part presents such ambiguous aspects of the HRBA operationalisation in the particular exercises of the GAs of UNAD and NUDIPU in terms of 1) disability and politics, 2) disability politics and 3) practical arrangements. Many warned me beforehand that the GAs are very political. To my experiences, they were indeed.

Disability and Politics: Interventions of the MPs²

Ugandan disability movement and politics have been deeply interconnected. The disability movement has developed by enlarging the political space for the representatives of PWDs and been morally supported by the ruling political party, National Resistance Movement (NRM). For instance, after the enactment of the Local Government Act of 1997, affirmative action policy has been introduced for the marginalized groups of people including women, disabled people, youth, and workers. Since then, they are represented in Ugandan politics at all levels including Parliament. Uganda has the quota system for five Members of Parliament (MPs) who are representing people with disabilities (PWDs): Four MPs from four regions (Central, East, West, North) and one woman with disability. One is deaf and others are physically impaired. Blind candidates also contested to the positions and failed. This, by the way, is an important piece of fact to remember for the following findings. Their sign language interpreters and personal assistants are paid by the government. An interesting fact is that in the 2006 election, two former MPs representing PWDs stood for the positions outside of the disability quota framework and also passed through. Both of them are WWDs: one with physical impairment and the other is blind. Therefore, there are seven MPs with disabilities in the Parliament at present who are relatively active in the disability movement, while a few more MPs from the North are also said to be PWDs but not active in the disability movement. All belong to the NRM. The disability quota is applied up to the village level, which created 47,000 disability councillors all over the country. Half of them are WWDs. Many of the politicians at various levels have worked as leaders of DPOs and still play a big role in the disability movement.

NUDIPU and UNAD are not exceptions. During the last term before the concerned NUDIPU GA, there was one MP with physical impairment sitting in the board of NUDIPU. This MP sat on the board since 1990 and was the longest serving board member. As for UNAD, the executive director and the secretary of the board are played by an MP who is deaf. He previously served as the chairperson of NUDIPU on the board for two terms as well. MPs representing PWDs tend to have clear connection to the disability movement as former or current DPO representatives. There is a mechanism why it has been so: the MP elections were held using the NUDIPU structure and mobilisation of PWDs by NUDIPU for the elections. More precisely, MPs are elected by four delegates from each of 56 districts, who includes woman, deaf, blind and physically disabled. They are in fact the same people who are invited to the general assemblies of NUDIPU. NUDIPU provides the register of the voters, which is administrated by the governmental electoral commission. NUDIPU

² This particular paper concentrates on the MP's interventions with a critical perspective. However, the Ugandan MPs with disabilities have been playing one of the key roles in major changes in the legislations among others such as the Local Government Act 1997 and Persons with Disabilities Act 2006. Their efforts and achievements in collaboration with the disability movement should not be undermined.

started to organise its general assemblies with the demography of the delegates since 1997, when NUDIPU had few District Unions. The Government was going to hold the election in 1998 to elect disability councillors from the village to district levels following the Local Government Act. Thus NUDIPU with the help of DPOD, a Danish DPO, quickly mobilised local PWDs to represent those positions. That is, the NUDIPU structure developed hand in hand with the development of the government's local structure. Therefore, "NUDIPU is regarded as an NRM mechanism and intimidation occurs during multi party elections (CDRN, 2009:27)." Recognised shortcomings of using the NUDIPU structure are many. Firstly, newly recognised disabilities other than the three major ones are not given entitlement to vote for their representatives. Secondly, only 56 districts can send voters, while there are 80 districts today. Thirdly, all these voters can elect four regional MPs regardless of the fact which one of the four regions they are from. As a result, the elected regional MPs can be different from the interests of the people representing the respective regions. Fourthly, it is said to be easy to manipulate the small number of voters. MPs are given "constituency development fund" by the government, which is literally meant for the development of the constituencies they represent, namely PWDs. Each MP gets ten million Ugandan shillings, which equals to 4000 Euros. Many interviewees and informants argued that this money is used for various election campaigns including the MP elections and GAs of DPOs.

Already in IDD event, those who wanted to support some candidates or who stand for positions in the forthcoming GAs were campaigning. "Campaigning" is about providing material and financial inputs as well as more democratic way of information and manifestation delivery. For instance, I observed one outgoing board member of NUDIPU offering free beer to people in the evening event. At this point, the campaigns came out from the underground at last, which enabled delegates to realise who would stand for different positions. Without expensive communication devices such as a computer and a telephone, physical contacts are the ways of campaigning for elections. Before the IDD event, few knew about who are standing for positions. After the IDD, the situation was totally different.

In UNAD GA which took place prior to NUDIPU GA, the deaf MP was vocal as the Executive Director (ED) and secretary of the board of the organisation. He presented various reports and answered to raised questions. In my understanding, he supported the outgoing chairperson to continue his chairpersonship. For instance, he tried to protect the chairperson and to answer the question when some raised a question on "corruption³" of UNAD during his public election campaign for continuing his chairpersonship, the highlight of the GA. The audience raised the voice against the ED not to intervene and insisted that the chairperson himself would answer the question. So he did. An MP appeared to the venue on and off, which spoke itself that he is in ally with the ED for the NUDIPU GA. All five MPs were present towards the end of the GA, while this MP visited the GA on and off throughout. It was reconfirmed when he was finally introduced by the ED that the MP is the honourable guest of the GA and was given a space for his long speech. The speech included the following clause:

³ This was the terminology used by the person who posed the question. This does not necessarily mean that UNAD is corrupted.

We support each other for the forthcoming elections. I am the board member representing [one of the four regions] in NUDIPU. And I am standing for the position. If you are from [the] region, please support me. I can bring three deaf persons to the board. Let's cooperate each other in NUDIPU GA. We have to choose very strong board. [Name of the ED] was the chairperson of NUDIPU and now an MP. We have to change the Constitution and allow MPs to become board members. This is my appeal.

He appealed the amendment of the NUDIPU Constitution which prohibits MPs to take the board members' positions. He was elected as an MP in 2006 when he was the board member of NUDIPU but remained in the board. This alliance between the ED and the MP was actually part of a bigger alliance. At this stage, I learned to know that all five MPs representing PWDs are supporting the newly elected chairperson of UNAD to stand for the chairperson's position of NUDIPU.

In the NUDIPU GA, all MPs were very alert. They even slept in the nearby hotels to secure their easy accessibility to the delegates during the time of GA for influencing the "self-determination" exercise in the election. Face-to-face meetings are the crucial interaction with the delegates. Thus during the NUDIPU GA, delegates had sleepless nights. Candidates and their supporters were knocking on the doors of delegates' hotel rooms all through the night campaigning for or against some. I stayed chatting with delegates until midnight for the two nights and saw MPs and others going up and down. Different groups of delegates were taken away from the venue to be treated on food and drinks. The night before the Election Day, one MP "betrayed" the alliance to support the UNAD chairperson. He started to de-campaign him instead. Some deaf delegates received mobile phone airtime worth up to 50,000 UGX (20 Euros) for changing their mind. That is equivalent to a one-month-income when engaged in a petty business in the city area. The voters were promised the vice-chairperson to be deaf, if they give up the idea of supporting the UNAD chairperson for the NUDIPU chairperson's position. An MP and others told me that the "betrayed" MP changed his mind because he got afraid of losing his own MP position. When the UNAD chairperson becomes the chairperson also of NUDIPU, he becomes too popular and the MP could not win in the next national election in 2011, because they are both from the same region to compete. The UNAD chairperson has enjoyed a strong support of the current deaf MP, which threatened this MP. With or without the influence of the MPs, the deaf candidate lost the chairperson's election against the blind, while a deaf woman was selected to the vice-chairperson's position unopposed: no candidate stood against her. Several informants told me that some candidates could not even stand for the positions for election due to the pressure of the MPs. In one region, the candidate had a personal conflict with an MP, and thus this MP campaigned against him. He was highly qualified and respected person among the disability community but could not go through. Many informants told me that this was the saddest thing happened during the GA.

Despite the various interventions by the MPs, the NUDIPU GA resulted in the intension to separate itself from the influence of the MPs and NRM. For instance, the GA reaffirmed that MPs should not be on the board and did not change the Constitution. As a result, the long-serving MP could not continue as a board member any longer. A journalist wrote an article, "MPs Barred from NUDIPU Board," in one of the major newspaper, New Vision, on 11.12.2008. The GA also decided to separate

NUDIPU from the national election exercise of MPs to be more accountable as a non-partisan NGO against the criticism that NUDIPU is a mechanism of NRM (CDRN, 2009:27). It was celebrated among the delegates that these were the clear signs of democracy, even against the hitherto powerful MPs. Self-determination as individual right of the delegates, however, was influenced by the politics in many ways.

Disability Politics: “I’m ready for the war!”

Not only politicians but also internal disability politics played a significant role in the GAs. UNAD is for deaf and NUDIPU for “every person with disability” according to their mission statements. However, different impairments, sex, age, education level and/or geographical locations among others have created certain hierarchy: the power is concentrated on certain group of people among the PWDs. This part elaborates the diversity of “PWDs” and the internal politics that were manifested in the exercises of the GAs.

The delegates’ demography implied disability politics. In UNAD GA, chairpersons of seven regional associations selected 20 delegates each for the GA. One region, Karamoja region, has been absent in the UNAD activities due to the remoteness, insecurity and perhaps also disability politics. Thus there were supposed to be 120 delegates from six regions. In reality, there were 109 delegates present. 50 of them were women, 69 youth under 30 years old. In the NUDIPU GA, 56 districts were entitled to send four delegates per district. The number of the districts still follows the older government structure, which increased to 80 districts today. At least one physical, blind, deaf and woman have to be included into the four delegates. In addition, four UNAB delegates and four UNAD delegates were entitled to vote due to the affirmative action policy. Furthermore, 14 outgoing board members are also entitled to vote. In total, there were 243 eligible voters present, of which 113 were women. 116 were categorised as physically disabled, 59 were blind, 57 were deaf and one represented three DPOs, namely Mental Health Uganda (MHU), Epilepsy Support Association of Uganda (ESAU) and Uganda Parents Association for Children with Learning Difficulties (UPACLED). Some did not have any impairment written down. 88 were youth. The delegates elected the following board members in respective DPOs: nine (eight in practice) UNAD board members consist of seven regional representatives (six in practice), one youth and one woman representatives, while 13 NUDIPU board members consist of eight regional representatives (four men and four women), two blind (one man and one woman), two deaf (one man and one woman) and one youth. Two (vice-chairperson and secretary) out of four executive committee members of the NUDIPU board are women. It was overwhelming to witness that more than 100 deaf from all over Uganda gathered together for this GA, let alone the GA of NUDIPU which mobilised the 243 delegates with one guide for each blind delegate and eight sign language interpreters for the whole deaf community. Both GAs were attended by many more observers relevant to the disability movement such as other associated member DPOs, MPs, supporters of candidates, donors and also passers by. The demography of the delegates and the board members superficially look democratic on paper, if not carefully investigated. This part firstly elaborates the disability politics through the analysis of the delegates’ demography.

First of all, the NUDIPU delegates who were entitled to vote were limited only to physically disabled persons, blind and deaf persons in terms of impairments, although

many more DPOs had appealed for full membership and the right to vote. On the first day, there was a demonstration of a DPO, Uganda Parents of Children with Learning Disabilities (UPACLED), to appeal the delegates to grant full membership to NUDIPU. They were given three minutes for their presentation. Mental Health Uganda (MHU) also disseminated handouts for appealing the same. After the heated discussion, the membership part of the Constitution was amended. Consequently All PWDs organisations of national character were granted the full membership and the entitlement to attend annual general assemblies (AGAs). The GA which is held every five years, however, was decided to maintain the status quo: only physically disabled, blind and deaf persons are entitled to vote. The AGAs are stipulated requirement in the Constitution, which had not taken place so far. Donors were sceptical for the NUDIPU to be able to raise funds for holding the AGAs. It was also taken for granted that the districts that are not covered by the NUDIPU structure (80 minus 56 = 24 new districts) remain not covered due to the financial constraint. The ones who hold the power of the “delegate status” did not give up their advantageous positions in the GA in any case, perhaps due to the financial constraint but also due to the disability politics.

Secondly, many of the UNAD delegates were illiterate and the secret ballots by writing down the names of the candidates they vote for did not work out in practice. This is due to the profound discrimination against deaf people in Uganda. Consequently, in the UNAD GA, it was agreed that the delegates can draw strokes in the secret ballots, such as “I” “II” and “III” instead of writing names. Deaf people’s education level is extremely low. Many of them even did not follow the discussions of the GA at all because they did not know the sign language, which was raised as a challenge. Nevertheless, the GA went on with the use of the Ugandan sign language. At this point, many were left out. The selection of the 20 delegates each from a region takes place by the choices of the chairpersons themselves. The delegates from the same region elect the forthcoming representative of the region. Naturally, the chairpersons choose those who are supportive to him/her to be re-elected. At the same time, multiple voices assured that the outgoing regional chairpersons deliberately choose lowly educated persons because they are easier to convince and avoid potential oppositions. When I socialised with the delegates during the days and nights, I realised that many women rather than men were both illiterate and did not have the skill of sign language. Naturally or coincidentally, four out of the six regional representatives’ positions were elected unopposed. This silently supports the aforementioned argument of the manipulation of the powerful ones. One position is meant for women representative, which was occupied by a deaf woman. Aside from that, there was only one women elected to the board. Therefore, two women and six men were elected to the board of UNAD. It was particularly interesting to observe the questions and answers raised during the GA prior to the election. A deaf woman questioned and the Executive Director of UNAD, the MP, answered:

Q (woman): Seven regions are not represented. One is left out. Karamoja is left out⁴. This is a big gap. We also have to have gender balance. Four regional model is better. I’m ready to fight for the gender balance. Many countries talk “Uganda is doing well.” But we are oppressing women. We are at the bottom regarding women. (applause)

⁴ The chairperson of UNAD had explanation why they were not there.

(omit)

Q (the same woman): Six regions are here but one forgotten. I know that the invitation letter was not sent there. This is a hidden agenda. The GA should be made by seven regions. The Constitution says that we elect seven regions, and so we have to follow that. Karamoja deaf should be included. It's discrimination against them. There is no democracy here.

ED: Now tea is ready. Let's go for a tea.

(omit)

Q (the same woman): There is no Karamoja delegates!

ED: It's time for tea. Closed!

This same tactic was used for several times to stop strategic discussions, including the time when the chairperson was making the activity report⁵. He started his presentation following the handout. He explained what the UNAD had achieved. Then, the handout had the section of the challenges. But he said, "The dinner is ready." And the chairperson's presentation was terminated there without going into the challenges. For those who are illiterate, they did not know that there was the section of challenges, which raised crucial issues for the delegates to discuss. The challenges included, "Deaf prefer cash handouts rather than accessing services or training to empower them. Sometimes they cannot participate in activities due to lack of money for transport to meeting venues" and "Some regional associations are not active at all, e.g. Karamoja has no functional executive committee." These imply that the activities have not accommodated deaf people who are vulnerable and poor, and thus would have been important to be discussed. The more educated and more powerful delegates used undemocratic methods to avoid certain discussions, which were unnoticed by many delegates.

Another tactic to end the discussion when the chair of the session agrees with the idea raised by one delegate is to ask from the audience, "Who supports the idea? Seconded by whom?" One more is needed to finish the conversation by declaring, "The idea was seconded by A." This was very widely used in both of the GAs in favour of the powerful and not necessarily representing the majority voices, which particularly made deaf delegates vulnerable in the NUDIPU GA. Both physically disabled and blind delegates could raise the voice and appealed, "Yes!" or "No!" when asked "Do you agree?", whereas deaf delegates' "voices" in sign language were disregarded in too many occasions because the responsible sign language interpreter for the voice of the deaf audience is one at a time and because others do not understand the sign language expressing their opinions.

I also observed among deaf delegates something similar in terms of power relationship. When nominations are called for some position, "vocal" people start to show the sign, "close," to express that the nomination should be closed after their supporting candidate has been nominated. Even when there was another nomination, sometimes the raised hands for nomination were not visible among the people who repeatedly show "close" signs. I observed at least one candidate who could not be nominated due to this among the deaf delegates.

⁵ The chairperson of UNAD disagrees with this.

Another challenge in the NUDIPU GA specifically for the deaf was the way how the election took place with the secret ballots. As was mentioned, many deaf delegates had a great disadvantage not being able to write down the names of the candidates. Each blind delegate had a guide of one's own, while deaf did not have such a personal assistant. In the very beginning of the GA, one deaf delegate publicly announced the challenge of the deaf delegates in the election process, which was recorded but literally ignored in terms of any reaction. The deaf delegates got frustrated as the GA proceeded. When a blind delegate made the next statement on the first day, the "war" between deaf and blind were re-confirmed:

The guides for blind people and sign language interpreters are totally different. Because we don't have eyes, we are vulnerable in movement. For instance, we cannot go to toilet alone. We cannot eat alone. The difficulties of ours are bigger. For you, deaf people, if some learns to know your language, you can communicate. The magnitude of our needs is totally different.

When resources are limited, rights of persons with different impairments collide. All rights should be equally important. Nevertheless, priorities are made in practice, that frequently infringes rights of the ones whose priorities are low.

On the second day when the election took place, one of the deaf delegates told me, "I'm ready for the war!" There was one deaf person contesting the chairperson's position in the NUDIPU GA. The other candidate was the outgoing chairperson who is blind. He was elected in the last GA by taking advantage of the alliances: then deaf and blind people were in ally and tried to go against those with physical impairments who are dominant in number. This blind person stood for the MP election and lost it. During the last national election in 2006, the alliance between deaf and blind is said to have fallen apart. Blind and deaf were supposed to support each other's candidates and would not set an opposition to each other's candidates. However, some candidate stood against the other and delegates did not support each other. As a result of the collapse of the alliance, the blind candidate did not go through. This was remembered bitterly in the NUDIPU GA, some interviewees explained in detail. In this regard, the "disability and politics" and the "disability politics" are overlapping. Others speculated that the UNAD GA just took place and the deaf delegates were still divided: those who supported the other candidate for the chairperson's position of UNAD are not supportive to the UNAD new chairperson yet for the NUDIPU chairpersonship.

Throughout the GAs, female delegates remained largely silent. I made a marking in my journal whenever females spoke up. According to my count, only 10-15% of the speakers were women in both GAs. Uganda is highly male-dominant, which was reflected in the GA exercise. That is, the local power structure affects the operationalisation of the HRBA in the GA practices.

After all in the NUDIPU GA, 10 out of 13 board members' posts were taken over by the same people. One of the re-elected board member was particularly contested due to the Constitution article that prohibits serving the same position for the third term. The appeal from the audience continued to be ignored, and so one blind person went to the front and forcefully grabbed the microphone and raised this issue to the audience,

despite of the fact that he was not appointed to speak. This, however, was solved with a very strange interpretation of the Constitution: “The Constitution was amended in this GA, and thus the content of the Constitution is valid only from today onwards.” That means, the clause to prohibit long-serving of the position cannot be applied to anybody, because the Constitution is amended in every GA. The board members have been highly criticised for their decision making power over various issues. This issue was particularly explicated in the NUDIPU organisational assessment report (CDRN, 2008) which was presented by a consultant during the GA. Many of the findings, however, were not discussed in the GA with or without intension. The delegates were not given the copy of the report, and so the information such as the following did not reach them: the chairperson of NUDIPU received 2876 Euros in 2008 including “untaxed monthly allowance of 450,000 UGX, 70,000 UGX worth of airtime per month, 50,000 UGX travel and subsistence for each board and sub-committee meeting”. The too expensive and too powerful board was considered “not justifiable” in the report (CDRN, 2008:31-32). Another source of information told me that the amendment ideas of the Constitution were also manipulated in favour of those who wanted to reinforce the status quo. District Unions documented and submitted their ideas of the Constitutional amendment to be discussed in the GA of NUDIPU, which was handled in regional workshops. However, in the board meeting just before the NUDIPU GA, it was decided that the discussion shall take place in the actual GA. And yet, the discussion did not properly take place with the presentations of those amendment ideas of the District Unions, several interviewees claimed.

In the opening of the GA, one representative of the “partner” (Norwegian Association of Disabled) made a speech and urged the delegates for democratic decision making:

[W]e as DPOs have the same responsibility to act democratically and transparently. We have to practice what we preach. Unfortunately, we too often see that leaders stay on and on, and that leadership development for the younger generations is not a priority, that women are not encouraged to take on leading roles. There are too many examples of moneys are being used to uphold structures as they have always been, rather than using them to create a change, and to give more disabled people the opportunity to become empowered, demand their own rights and live an independent life.

This precautionary speech, however, was not well taken into consideration in the exercises of the GAs in both DPOs.

Practical Arrangements

The practical arrangements of the elections of the magnitude required a lot of preparation beforehand and works at site so that they go as smoothly and fairly as possible. I witnessed staffs of both DPOs worked very hard for the GAs. However, there have been rooms of improvement in the practical arrangements of the GAs.

In both GAs, the officially registered delegates needed to carry their name badge to distinguish them from observers who do not have the right to participate in the decision makings. The badges were not put by many. In the UNAD GA, I observe some carrying a fake badge which was found out by a staff. Some official delegates were not even deaf, which could not be screened in advance. In the NUDIPU GA, the

badges of many delegates were not ready by the time the GA started. Actually, some of them were not ready until the end. Thus some had to carry a stamped document of NUDIPU to prove that they are officially registered delegates. Without delegates having any ID, it was difficult to identify who they are and particularly how old they are. Those who are under 30 years old had the right to vote for the youth representatives in both GAs, which were carried out with their self-claim of their age.

Meals were served at certain times regardless of the progress of the GAs. Thus many teas and meals were served in the middle of the GA activities, which took many delegates away from the important discussions. At the same time, during the election of the NUDIPU GA, people were walking around for eating and other reasons, while a few staffs distributed the ballots. For instance, the total number of votes for the chairperson's election was 231, while that for the treasurer was 189 only. Therefore, the possibility cannot be denied for some getting a few votes from different staffs, which was claimed by many.

The biggest surprise is the fact that I was mobilised for managing one election in the NUDIPU GA. When the tea was served, I went back to the venue and was called up to be responsible for the election of the Central Region. I was given a list of delegates who are entitled to vote, ballot papers and a locked box with the key. There was no explanation how to handle the election, while I did not have any previous experiential knowledge how the election in this particular GA should go. We quickly decided with another observer to firstly check whether all delegates are present, secondly asked nomination of candidates, thirdly allowed the candidates to make public campaign speeches, fourthly gave out the ballots and fifthly asked district by district to come out for voting. We checked the names of the delegates from their badge or their stamped documents, and then allowed them to vote one by one. When they voted, we count the vote and checked whether the final votes matched the count to avoid any additional vote. Four regional elections took place in the same venue at the same time. Whenever one was elected in one region, a huge applause occurred. Thus the noise disturbed the election exercise to a great extent, as all guidance and speeches were practically impossible to hear for blind and physically disabled delegates. Only deaf delegates properly heard them through the simultaneous sign language interpretation, if they managed to see the interpreters at all. The space for each region was very limited. Thus calling up the delegates to come near the box to vote was rather complicated and time-consuming. We count the votes together and declared the winners. This was the procedure that we took after a quick thought. However, other observers who were appointed for the similar positions might have taken different ways, which could be better or worse. I observed other elections in which some observers were giving out ballot papers to the raised hands without checking their badge or documents. In a way, the sudden mobilisation of observers was fair as we did not know that we were in charge. Thus we could not have been influenced or manipulate the votes in any way. However, in another way, at least I was totally unprepared for this role. I could have managed the election in a better way, if I were given more time and information beforehand.

The GAs that I observed were said to have gone very smoothly as both of them completed by mid-night. Previous GAs went on even later. The staffs were particularly satisfied for their achievement as the practical arrangements had greatly improved. The aforementioned points, however, were some rooms of improvements

from my participatory observation. The operationalisation of the human rights-based approach in terms of the GA exercises implied many pitfalls of the approach in practice, which will be analysed in the following part. Prior to that, the strength of the HRBA is reviewed.

The Strengths of the HRBA in the GAs of Ugandan DPOs: Self-determination, Solidarity and Empowerment

The previous parts concentrated on the ambiguous and undemocratic ways of the operationalisation of the HRBA. This study, however, is not aimed at criticising the two DPOs that kindly invited me for their GAs. On the contrary, the aim is to learn from good practices and challenges in the operationalisation practices of DPOs in Uganda. Good practices as well as challenges should be appreciated and elaborated so that the HRBA would become more useful and usable in practice. This part focuses on the strengths of the HRBA in the practice of DPOs in Uganda. In general, the significance of the HRBA to disability in development is four-fold (Katsui & Kumpuvuori, 2008:234): One implication of this approach is that it effectively draws all human beings into mainstream discourse, and includes the most vulnerable groups of people such as PWDs. Second, the approach requires rights-based action instead of charity, which has been predominant. Thus, the actual change must take place in the operationalisation. Third, the approach stipulates state obligation to secure the human rights of concerned people. Fourth, this approach demands transnational obligations, which is the biggest difference between the human rights based approach and the social model of disability. In the specific context of the GAs of Ugandan DPOs, self-determination, solidarity and empowerment as a result are the key words in terms of the strength of the approach.

The GAs are very expensive as they mobilise such a significant number of delegates to one venue. They are financially supported by various Northern partners and donors⁶. One Northern partner DPO staff explains that GAs are not what many donors are willing to fund because “[t]hese are typically costs that don't lead to direct changes in the lives of the target group, and which therefore most probably are less sexy to fund in an time where development agencies experience a high pressure on delivering concrete and measurable results in people's lives from their funding.” Despite that, this Northern DPO has supported the GAs and anticipates to continue the support for the forthcoming GAs. She argues,

Although GAs don't guarantee for a democratic and transparent organization, we perceive that holding GAs according to your own constitution is an indication of that the organization is striving towards democracy, and a sound organizational culture. [Name of this Northern DPO] is a DPO itself, and it would be very awkward for [the name of this Northern DPO] to deny our sister organizations to spend some of the funding on the governing bodies of the organization, when we know how important they are (personal contact on 6.2.2009).

⁶ Ugandan DPOs often call their Northern counterparts “donors” or “parents” by placing themselves lower in the hierarchy, while Northern ones call the Ugandan counterparts “partners” and “sisters.”

This statement coincides with another Northern DPO staff that also supported the GAs,

One of [name of this Northern DPO]'s aim is to build the capacity of her partners, particularly DPOs. Capacity building takes different forms. One key indicator that we put forward to measure success of the capacity building programme is presence of democratic and representative DPOs. A GA is one way that PWDs are able to demonstrate democratic and effective governance. A GA is a high level policy making body which if handled well and with maturity the people elected as officer bearers become cornerstones in the implementation of the activities of the organisation. That is why [the name of this Northern DPO] supports GAs of DPOs (personal contact on 6.2.2009).

The third Northern DPO staff also made very similar statement (personal contact on 26.2.2009). That is, the GAs are regarded as integral parts of organisational activities towards good and democratic governance of DPOs, if implemented well. Self-determination exercised in the GAs is the sign of democratic capacity, which is not a charity but an entitlement. PWDs who are too frequently and disproportionately at the bottom of the social stratification gain the decision-making power for their own DPOs, as non-disabled peers do in their NGOs. Thus ownership and participation of PWDs in the form of GA activities of their DPOs is a process towards mainstreaming and part of mainstreaming itself.

Another expressed strength is the attempts towards solidarity at different levels. For instance, the Northern partners express their solidarity by calling the Ugandan DPOs “sister organisations” and “partners.” This solidarity highly motivates the Northern DPOs to financially and morally support the GAs because they also use part of their budget for upholding such regular assemblies for collect decision makings. Similarly, the GAs promoted the solidarity among the delegates by frequently referring them to “brothers” and “sisters” who share similar experiences and thus the identity of PWDs to attain the same goal of human rights. Many speakers stressed that the delegates own the DPOs and that they are “family.” The deliberate choice of these solidarity-oriented words was partly to control over the situation where the dissolution and dispute among the delegates were manifested in the election activities but also to strengthen the disability movement. These “participation forums” contribute to produce collective identity (Barnes et al, 2006:201). Ownership and togetherness were experienced in the GAs (famle deaf delegate to both GAs, personal communication on 2.3.2009). In this sense, the GAs are part of the “process” of constructing an action system (Melucci 1996:70 cited in Barnes et al 2006:201).

The turn up rate is nearly 100%, which is an amazing number. This shows the high commitment of the delegates to the GAs⁷. The fact that PWDs were eloquently making different appeals and negotiating their own rights was an empowering process. This political space for exercising their right to vote made the delegates realise their power both in good and bad ways. Each delegate was treated as an important voter and a decision maker throughout the GAs. It was the delegates’ entitlement to judge

⁷ Some ironically pointed out that the turn up rate is so good because they are paid high transportation cost. This subsistence culture introduced in the development cooperation activities has been highly criticised for demoralising and discouraging voluntary participation.

the accountability of the office bearers in the form of elections (male with physical impairment, personal communication on 26.2.2009). The right to vote was equally distributed to each delegate despite the power gaps not only among the delegates but also with the semi-external actors such as MPs. The elected board members are responsible for the steering of the DPOs as office bearers, without which DPOs would collapse (female deaf delegate to one GA, personal communication on 27.2.2009). The delegates' participation in the GAs facilitated to disconnect the image that PWDs are poor and passive. Particularly, female candidates were more visible than ever before. For instance, the first female contestant in its history stood for the chairperson's position in the UNAD's GA (male deaf delegate to both GAs, personal communication on 6.3.2009). The GAs provided the space for operationalising their rights. In other words, the delegates were both individually and collectively empowered through the GA exercises, at least to some extent in theory. The decisions made in the NUDIPU GA to become independent from MPs and NRM against the pressure proved the realisation of their own decision-making power.

Concluding Remarks with Lessons Learned from the GAs of Ugandan DPOs

As described above, the HRBA exercised in the GAs of Ugandan DPOs has left some important implications for it to become more useful and usable in its operationalisation. In short, the existing power structure matters: it deeply affects self-determination, solidarity and empowerment, even when equal rights to vote are entitled to each delegate under the principles of equality and non-discrimination. This part elaborates the power in relation to the operationalisation of the HRBA.

Existing Power Structure Matters

When elaborated the demography of the delegates and how they "self-determine" various matters during the GAs, it became clear that operationalising self-determination cannot be taken for granted. Firstly, who is "self"? In this specific context, PWDs are at stake (even though in the UNAD GA, several non-deaf delegates were invited). Then secondly, which PWDs are making decisions? Who "determines"? Are they based on voluntary participation? No, they are the powerful PWDs in the existing power structure of Ugandan PWDs. It is evident that those who are better integrated into social networks are more likely to be recruited to social movements and that among the 'core group' of such movements are found a high percentage of people from 'mid to high' social positions (Della Porta & Diani, 1999 cited in Barnes, et.al. 2006:196). The delegates of the NUDIPU GA were the elected ones in their district GAs with the criteria of at least one woman, one deaf, one blind and one physically impaired person. In the UNAD GA, some delegates were invited to facilitate the re-election of the same people easier and thus were illiterate, for instance. However, they were also somewhat "powerful" as they have the direct connection to the most powerful PWDs who selected them as the regional delegates. In the NUDIPU GA, they are one of the three impairment groups: hearing, visual and physical impairments. In other words, all the other impairments are left behind in terms of the right to vote except for one board member entitled to the representative of three DPOs including MHU, ESAU and UPACLED. In Uganda where medical services are not accessible to a great extent particularly due to the physical and financial constraints, persons with easily observable impairments tend to be recognised as PWDs based on subjective diagnose, while others tend to be left behind

even in the disability movement which is supposed to accommodate them. At the same time, the gender imbalance was obvious in terms of voices raised during the GAs: most of the opinions were made by male delegates, whereas female delegates remained largely silent. This is the reflection of the male-dominant society which is the local power structure (Ministry of Finance, Planning and Economic Development, 2008: 53-78). Furthermore, a group of the most powerful PWDs, MPs, had a lot of influence over the decision making process of the delegates. The MPs have much better access to various information and resources, which contributed to the power gap with the delegates and ended up in the influence: some coercive and other simply convincing political campaign. In theory of decision making, when options are not clear to the decision makers due to lack of information, for instance, they are particularly vulnerable to the influence of others (Jenkinson, 1993:367). Under this condition, especially when the candidates and their supporters involved money, voluntary decision making becomes challenging when many of the delegates are poor due to the severely discrimination surroundings and their impairments. In other words, there is the phenomenon of colliding rights: already powerful ones want to protect their individual positions in the name of “right to participation in political and public life” as in the Article 29 of UN CRPD, while others would like to raise gender equality, non-discrimination of persons with different impairments as collective rights of representation. Consequently, priorities tend to be made in favour of already powerful, vocal and/or visible people too often reflecting the existing power structure at various different levels. This internal dynamics of interaction is important to understand.

Empowerment, Self-determination and Representation

Empowerment of persons with disabilities has been linked to the decision making power (Jenkinson, 1993; Finlay et al, 2008), and thus self-determination. Empowerment with individual approach has been criticised as Eurocentric. For instance, van Houten and Jacobs (2005:644) argue that the conceptualisation of citizenship reflects western view of human beings as being autonomous and self-reliant and often understood as “(political) decision-making, deliberation and argumentation, the free and critical mind (ibid.)” In Uganda, individuals are part of bigger units such as families, clans, (geographical, social and cultural) communities and so forth. Hence, it is self-evident that the local power structure matters. The empowerment concept, therefore, needs to pay attention also to the differences and dynamics of different stakeholders in the context, while equality discourse tends to undermine differences (ibid.645). “Contextual variables” need to be taken into account (Jenkinson, 1993).

For example, solidarity was another strength mentioned in the previous part. Solidarity is characterised as a collective identity, an awareness of equality (or a problematisation of inequality) and an ability to articulate the priorities of the most marginalised groups of people (Katsui, 2009:22). The GAs brought about the collective identity as PWDs who generally face severe discrimination against them, which was reassured⁸. However, the GAs highlighted the diversity under the veil of “PWDs” particularly in the course of election activities rather than bringing the

⁸ The essentialisation of individual identity fixed as PWDs is problematic because the delegates change their identity depending on time, place and occasion: sometime they feel their identity as women, fathers, ethnic groups and so forth more important than the identity as PWDs. This identity question is discussed elsewhere (Katsui, 2008).

delegates together, as have been highlighted with various anecdotes. Inequality among the delegates was evident before addressing the equality of PWDs vis-à-vis peers without disabilities. The inequality, however, was not much problematised and even ignored when raised as an issue to discuss. The existing inequality and the power structure tended to be taken for granted in favour of the powerful ones. The last characteristic of solidarity, an ability to articulate the priorities of the most marginalised groups of people, therefore, was naturally paid little attention to in the power struggle of individuals in the GAs. That is, to some extent the GAs might have disempowered and further marginalised already marginalised groups of people in the disability movement, while reinforcing the status quo in favour of the powerful.

This phenomenon has been observed already long in the history of social movements. Van Houten and Jacobs (2005:648) claim,

When a social movement wants to gain power, a stronger organisation is needed and the organisation must grow. This demands a more bureaucratic form of leadership and some degree of specialisation and division of labour. Ordinary members no longer understand their leaders and vice versa. The social movement has been transformed into an oligarchy, ruled only by a few people.

This is known as “‘The Law of Michels’, the Iron Law of Oligarchisation” (Michels, 1911 cited in van Houten and Jacobs, 2005). Representation is not straightforward, when its negative side significantly affects collective goals to be achieved. Representation has the potential to increase the distance between participants and non-participants (Barnes et al. 2006:205), which has to be beard in mind.

At the same time, the empowerment effect cannot be limited to the official venue of the GAs. The empowerment effect takes place also in different localities or families where the delegates are from after participating in the GAs. The immediate material impact comes from the transportation costs paid by the DPOs for the delegates to participate in the GAs. It is overlooked truth that it costs much more for many persons with disabilities to travel the same distance compared with peers without disabilities because some public transport vehicles charge even three times more fee for wheelchair users, for instance (Ministry of Finance, Planning and Economic Development, 2008: 104). Nevertheless, the amount paid as transportation compensation was significant for any delegate to my knowledge. This financial impact might lead to empowerment of the families of the delegates as a whole. The empowerment effects outside of the official venue are perhaps more important to elaborate in the future research taking into account the local power dynamics among different stakeholders.

The GAs are surely extreme cases in which power is supposed to be negotiated. Nevertheless, it is also recognised as one of the most visible exercises of the HRBA and thus important to be critically elaborated. As mentioned before, this is an essential part of organisational activities of Ugandan DPOs, at least according to their Constitutions, (although some DPOs cannot afford to organise their GAs and/or annual GAs).

Disability is above all a critical human rights issue and respecting these rights is critical for the sake of justice, equality and inclusion. To achieve a genuine development process, DPOs must address human rights issues too (The Secretariat of the African Decade of Persons with Disabilities, 2009:7).

Disability and human rights are inseparable today. Evidence-based knowledge on the operationalisation of the HRBA to disability in development, however, has still been limited. With the case study of the GAs of Ugandan DPOs, this paper presents the concluding remarks of the following implications for better operationalisation of the HRBA: The local context, both internal and external power dynamics in which DPOs operate, has to be extensively exhausted so as to deeply understand the operationalisation of the HRBA by the DPOs. Particularly, “empowerment,” “self-determination” and “representation” have to be carefully investigated in each context where the HRBA is implemented.

Acknowledgement

I appreciate the invitation of UNAD and NUDIPU to have enabled me to participate in their general assemblies. Many Ugandan delegates as well as Northern partner DPOs took their time to share their experiences and opinions with me. A number of them continued to provide me with further information through e-mail exchanges. I am very grateful for their continuous support to me and my study. I would like to thank Edson Ngirabakunzi, Deborah Iyute, Rehema Namarome, Meldah Tumukunde, Abdul Busuulwa, Christine Lule, Ambrose Murangira and Betty Kyogabirwe for their insightful comments and inputs on the previous versions of the article. The draft paper was presented in the 10th Nordic Network on Disability Research Conference in April 2009, and received valuable comments. The fieldtrip to Uganda in January and February 2008 was financially supported by Tokyo Foundation, while one in December 2008 by Nordic African Institute. Finnish Academy has been financially supporting the whole project for four years. I am very grateful for their supports. However, the views expressed in this article are mine and they have no responsibility for the content and possible mistakes.

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