

DISABILITY, HUMAN RIGHTS AND HUMAN SECURITY

JUKKA KUMPUVUORI ~ HISAYO KATSUI

Jukka Kumpuvuori is a lawyer and a disability activist in Finland. He graduated (LL. M.) at University of Turku and is now writing his PhD on human rights of persons with disabilities in Uganda at the Institute for Human Rights at Åbo Akademi University, Finland. Mr Kumpuvuori has authored several legal publications on different themes of disability and human rights and is active in disability rights advocacy in Finland and globally, especially in the development context.

Dr Hisayo Katsui is a senior researcher at the Institute for Human Rights at Åbo Akademi University, Finland. Katsui and Kumpuvuori are taking part in the research project Human Rights-Based Approach to Disability in Development: Interplay of Disability-Sensitive Development Cooperation and National Policy in Uganda. Ms Katsui holds a PhD in Social Sciences from Helsinki University, Finland. Her academic interests are on disability, human rights-based approach, civil society and development. Homepage: <http://blogs.helsinki.fi/katsui/>.

INTRODUCTION

ON 3RD OF MAY 2008, THE United Nations *Convention on the Rights of Persons with Disabilities* entered into force, which exemplifies the era when human rights have entered into the arena of both disability and development discourses as a key concept. A human rights-based approach (HRBA) has become increasingly important in tackling existing inequality at different settings.

At present, the number of persons with disabilities (PWDs) around the world is estimated at 650 million, which occupies 10-12% of the total population. The human rights-based approach to disability connects this largely neglected part of the world population with the development discourse.

A human rights-based approach is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights. It seeks to analyse inequalities which lie at the heart of development problems and redress discriminatory practices and unjust distributions of power that

impede the development process (OHCHR, 2006). The human rights ideology has four implications. First of all, it effectively draws all human beings into mainstream discourse, and includes the most vulnerable groups of people such as PWDs. Secondly, the approach requires rights-based action instead of charity, which has been predominant. Thirdly, the approach stipulates state obligations to secure the human rights of concerned people. Fourth, this approach demands transnational obligations (Katsui ~ Kumpuvuori, 2008).

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 [organisation of PWDs] must address human rights issues too (The Secretariat of the African Decade of PWDs, 2009:7).

Human rights and disability are inseparable concepts today. This article elaborates this realm with the case studies on the advocacy work of organisations of PWDs related to the enactment of specific laws in Uganda and Finland. Firstly, the cases are respectively described. Secondly, forms of advocacy are analysed with the special

attention to political and legal advocacy. Thirdly, challenges of the advocacy processes are reviewed. Fourthly, the personal experiences of the studied advocacy activities are linked to the concept of human security. The concluding remarks present a few observations from our case studies. The arguments are enriched by interviews with key stakeholders of the cases in both countries that were conducted during 2008 and 2009. Disability study is multidisciplinary in nature. This article is written by two scholars from different fields, namely law and social sciences. Hence, the analyses utilised in this article are also multidisciplinary: evidence-based situational analysis combined with legal and theoretical ones. That is, the conclusions drawn in the article are the result of the effective combination of different methods of analysis.

UGANDAN CASE: LOCAL GOVERNMENT ACT 1997

The Local Government Act 1997 legally secured the political representation of PWDs in all local government structure

DISCUSSION

“ Thus freedom now so seldom wakes, The only thorb she gives, Is when some heart indignat breaks, To show that still she lives. ”

THOMAS MOORE

with the introduction of quota system. The Act was enacted as a series of decentralisation efforts of the ruling political party, the National Resistance Movement (NRM) since 1986. After the military regime of Idi Amin (1971-1979) which centralised the power, and the following regime of Obote (1980-1985) that did not take any major change in its structure, there was the vacuum of local government structure. Therefore, the new NRM regime and the President Museveni gave high priority to democratic governance (Mugabi, 2004). In 1987, right after the change of the regime, National Union of Disabled Persons of Uganda (NUDIPU) was established as the umbrella organisation of 17 DPOs (Ndeezi, 2004:12). NUDIPU is said to be “one of the strongest national advocacy and lobbying organisations championing the cause of marginalised groups in Uganda” (Ndeezi 2004:17). The ruling political party, NRM, has morally facilitated the growth of disability movements (*ibid.* 17). The Affirmative Action Policy 1989, for instance, promoted representation of the marginalised groups including PWDs.

In the Constituent Assembly for the formation of the Constitution in 1995, late Eliphaz Mazima with physical impairment, who had the background of disability activist and the first elected chairperson of NUDIPU, represented PWDs and the Constitution succeeded in having many clauses related to PWDs (Ndeezi, 2004:23; Kokhauge, 2008).

It has become a legend among the present disability activists how Mazima managed to convince other delegates, especially other vulnerable groups (Millward et al, 2005:161; Asamo, 2008). Consequently, the 1995 Constitution includes the following clauses among others:

Rights of PWDs.

35. (1) PWDs have a right to respect and human dignity and the State and society shall take appropriate measures to ensure that they realise their full mental and physical potential.
- (2) Parliament shall enact laws appropriate for the protection of PWDs.

In 1996, national elections took place using affirmative action policy following the Parliamentary Statute (Government of Uganda, 1996) that made five Members of Parliament (MPs) with disabilities representing PWDs (Millward *et al.* 2005:154). Along the same line, the Local Government Act resulted in 47,000 disability councillors representing PWDs at different levels of the local government structure, half of which are women with disabilities. The representation has been gradually making changes on the grassroots level as these councillors have become the channel to relevant decision makings (Lule, 2009). They have been improving the quality of life of PWDs at different levels. The Act is cited as a “top-down initiative” of the NRM rather than a movement-oriented bottom-up initiative (Tamale, 1998:255), which has some implications. An MP, Sekabira (2009), and Mwesigye (2009) point out the good political will of the

President as a positive factor in the formation of the Act. However, including PWDs into the Local Government Act was not automatic. There was a vigorous advocacy for realising this Act to be inclusive of PWDs.

FINNISH CASE: PERSONAL ASSISTANT SYSTEM

The Personal Assistant System for PWDs is based on the Act on Services and Support for Persons with Disabilities (law 380/1987, later ‘Disability Service Act’). It provides support for PWDs to enable them to hire a personal assistant to assist them in their daily activities.

From the beginning of the enactment of the Disability Service Act, the right to sustain a personal assistant has been a discretionary right, in which the municipality can legitimately argue on the lack of resources to deny PWDs from getting the support. This has led to the highly varying situation of PWDs needing personal assistance depending on what is their place of domicile.

The problems in the Personal Assistant System also have their constitutional dimensions, which relate to the fact, that the Disability Service Act was enacted before the constitutional reform in Finland that took place in 1995. Because of this, the Disability Service Act has not been looked at from the point of view of a strong system protecting the fulfilment of basic rights of

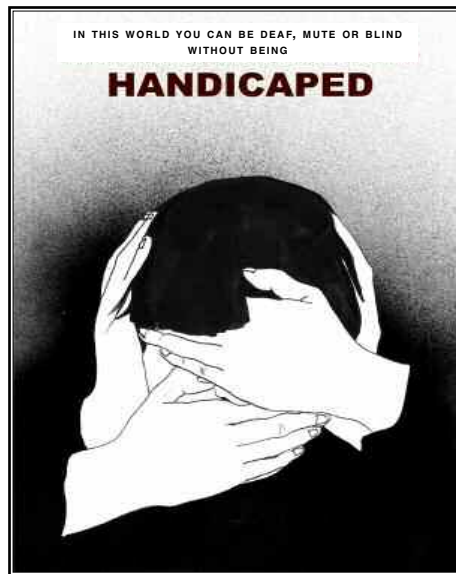
individuals. In the context of Personal Assistant System and PWDs, Section 19 of the Constitution of Finland (Act 731/1999) is particularly relevant. It regulates as follows:

Section 19 - The right to social security.

Those who cannot obtain the means necessary for a life of dignity have the right to receive indispensable subsistence and care.

The right to receive indispensable subsistence and care means that PWDs need to be provided personal assistance to enable them to live a life of dignity. Hence, the legislator has the obligation to make laws that guarantee this right, i.e. to make effective laws on the Personal Assistant System (Tuori, 2005:3). Maintaining the right to a personal assistant as a discretionary right or a moral obligation cannot be seen as an effective legislation.

The goal of the organisations of PWDs has been that there would be a legislative change of the right of PWDs to a personal assistant from a discretionary to a subjective right. The pressure from organisations of PWDs to change the Personal Assistant System was increasing towards the end of the term of Matti Vanhanen’s I Cabinet (24 June 2003 - 19 April 2007). Especially the Association of Employers of Personal Assistants was performing very intensive and sophisticated political lobbying using the latest forms of electronic communication towards decision makers and also contacting them by telephone and physically. In autumn 2006, when the campaigning for Parliament elections of March 2007 was very heated,



a demonstration took place in the stairs of the Parliament on 29 September 2006 to increase the pressure on the Government. Another demonstration took place on 6 December 2007, the Independence Day of Finland with the slogan, “Independence for PWDs”. As a result of all these advocacy works, 2008 became a groundbreaking year in the development of the Personal Assistant System.

Practically the same core group that had been active during the whole process, negotiated intensively with the Government. It is significant that they actually negotiated. There was enough political support for the change because this was a very valuable source of information and ideas to the Government. The Minister for Social affairs, Paula Risikko, led the process, which resulted in the proposal to change the law in October 2008. The proposal was accepted by the Parliament on December 2008 and the amended law enters into force on 1 September 2009.

FORMS OF ADVOCACY: POLITICAL OR LEGAL?

In the context of DPOs, legal advocacy and political advocacy can be distinguished as follows. In legal advocacy, both arguments and methods used are primarily legal. This means using arguments such as “We, PWDs have the constitutional right to X” and employing legal methods such as filing complaints to legal bodies. In political advocacy, both arguments and methods used are primarily political. This means using arguments such as “You politicians should change the law, otherwise your political support of our group will decrease rapidly” and employing political methods such as negotiations with the politicians. The two types of advocacy do not exclude each other. The following analysis on the two cases reveals that the two support each other.

In the Ugandan case, disability activists recognise the process as political advocacy. This is due to the inseparable relationship between NUDIPU and MPs (Katsui, 2009). Almost all the MPs with disabilities have the background of disability activism prior to their political positions. Therefore, even though their ideological background of the advocacy work is much based in the human rights framework, such as the human rights-based 1995 Constitution and the 1989 Affirmative Action Policy, it is considered as a political advocacy, not a legal one. The advocacy for the Act did not utilise legal institutions, which led to the recognition of political advocacy.

“Multi-party politics” was introduced only in the national elections of 2006, which to some extent began to facilitate legal processes against the ruling party, NRM. The concerned Act was enacted during the time of the nation building, which had minimised a confrontational approach including legal measures particularly against the NRM. In this way, PWDs were positively included as part of an important constituency for the common goal of democratic nation building. Only after the enactment of Persons with Disability Act 2006, legal advocacy means started to be used for revealing violation of human rights against PWDs. NUDIPU and other Ugandan DPOs have been involved in filing court cases based on the Persons with Disability Act. However, the recognition of human rights among PWDs on the grassroots level is too limited despite the great efforts

of sensitisation and awareness raising of NUDIPU (Kinubi, 2008; Ndeezi, 2008). Even lawyers working for PWDs try to settle cases without going into court because of resource constraints (Kanushu, 2008). Purely legal advocacy, therefore, is a very recent phenomenon as well as “last and expensive choice” in Uganda.

In the Finnish case, DPOs had lobbied also before to decrease the regional inequalities in the implementation of Disability Service Act, also in terms of services and support other than the Personal Assistant System. The way to make a societal change had been very politically (mostly non-party) oriented. The first sign of an awakening in the field of legal advocacy came about in 2005, when a prominent legal scholar Professor Kaarlo Tuori was asked by the Association of Employers of Personal Assistants, the organisation established to advance this particular advocacy, to write a constitutional analysis of the Personal Assistant System and the grounds for securing a life of dignity for PWDs through that system (Tuori, 2005). A constitutional analysis from a prominent legal scholar was not at all a minor change. It was a totally new way of analysing the situation of PWDs also outside the scope of the Personal Assistant System, as there had not been many writings on the rights of PWDs, particularly not from professor-level legal scholars. Besides the *per se* importance of the analysis, the importance of disability activists asking for it was a huge change. It meant moving towards a more legal way of thinking toward societal change, towards legal advocacy. The importance of this analysis in the whole process cannot be undermined:

“During the fight, the analysis of Tuori acted as a cornerstone all the time. In the final stages of the fight, it was not so much marketed because its arguments were well accepted even amongst the preceding Parliament (Tiri, 2009).”

The analysis of Professor Kaarlo Tuori can be said to have had an instrumental role with regard to the political advocacy, which in an interesting aspect in relation of these two types of advocacies. The arguments of the analysis were later used in actions of political advocacy.

After the demonstration a group of people and organisations supporting them started a new project that was very human rights based. They decided to write a complaint to the Chancellor of Justice. In the complaint the organisations asked the Chancellor of Justice to investigate, whether Matti Vanhanen’s Cabinet had neglected the development of the Personal Assistant System, even though they had the legal obligation. The complaint was signed on 24 October 2006, about a month after the demonstration. Even though the organisations were serious about the legal grounds of the complaint, it was clear that the main purpose of filing it was to get political pressure to Matti Vanhanen’s Cabinet. Even though the result of the complaint was not the one DPOs wanted, legal machinery was used to make a change in the political sphere. Again, legal and political advocacy intertwined.

The analysis of the two cases allows us to understand that the concepts of legal and political advocacy intertwine in practice. Particularly, legal arguments around the human rights ideology based on existing laws and constitutions have been utilised in both cases. When it comes to methods

of legal advocacy, such as filing complaints, it is ultimately seen as a “final stage.” Another observation is that even if methods of legal advocacy are used, they are primarily for getting extra-arguments for political advocacy. Legal advocacy is, however, increasingly emphasised in both countries particularly in terms of arguments but also means. Utilisation of legal advocacy more in the future is very likely among DPOs in both countries.

CHALLENGES OF THE ADVOCACY PROCESS

In both cases, the desired laws were realised or are about to be realised. The law making is only a process of disability movements for “putting things correct that had gone wrong for decades, if not centuries (Mwesigye, 2009).” The processes, including the implementation of the laws, have entailed a number of challenges in both countries. This part sheds light on those challenges so as to highlight the specificity of disability in human rights advocacy works: discrimination (OHCHR, 1996-2003), heterogeneity among PWDs (Katsui - Kumpuvuori, 2008) and resource constraints (Shakespeare, 1993).

First of all, severe discrimination and ignorance of the society is a common challenge both in Uganda and Finland. This means in practice that PWDs and DPOs are considered responsible for the required changes because others are not well aware of their needs and rights. This gives massive stress to disability activists as they have to make necessary social changes for the human rights of PWDs in a discriminatory society, the personal experiences of which will be elaborated further in the following chapter. In the Ugandan case, the enactment of the Act expected that the NUDIPU had had a structure in all districts to be able to elect those disability councillors, which it did not have before the Act. NUDIPU was a Kampala-based organisation then. Nevertheless, NUDIPU realised this as an opportunity and created the nation-wide structure “with the record fast time (Kokhauge, 2008)” which enabled the election of the 46,000 disability councillors in time. As many of the disability councillors did not have qualifications, NUDIPU created an “empowerment package” so that they could negotiate with others in the decision making processes. Consequently, PWDs have been officially mainstreamed in the political space in practice, while empowerment of them is still lagging behind. The policy cannot solve the discrimination (Tamale, 1998:255). This has been seen as one of the biggest challenges of this Act.

In the Finnish case, DPOs have trained PWDs to become “bosses” over their personal assistants. Being a boss to somebody is not easy. It is especially not easy when one has not done it before, which is usually the case when a PWD hires the first personal assistant. The Threshold Association, which is a human rights organisation of PWDs, started to organise “Boss Trainings” with the aim of empowering PWDs to become bosses. The level of knowledge on the rights and obligations relating to being a boss was very weak among the disability community. Over the decades, the knowledge has spread but as there are always new PWDs who become bosses, the training is ongoing. The training is predominantly organised based on peer-support. In both cases, DPOs are taking the heavy responsibility in the implementation of laws.

Secondly, human rights advocacy of DPOs means in practice that heterogeneity among PWDs has to be overcome and harmonised as one appeal. In the Ugandan case, the grouping of “PWDs” was not questioned.

“When it came to fighting own issues, for the issues of people concerned whom I’m representing, you know, we could forget those differences, and we can fight for the issues of PWDs. I think also that was very fundamental (Nalule, 2008).”

It was questioned when the demography of the elected 47,000 disability councillors was clarified after the election. Among the elected councillors all over Uganda, marginalised groups, such as deaf (Murangira, 2008), children with disabilities and their parents (Millward et al, 2005:161) among the PWDs are represented to a very limited extent or are non-existent.

In the Finnish case, a lot of conflicts among different groups of PWDs and their organisations arose during the advocacy process. Conflicts were about disagreements in some definitions in the draft laws that were presented by some DPOs and the Government. Few persons with physical impairments were the leaders in the series of activities. The timeframe was too tight to get consensus from the individual members of the organisations. One interviewee describes this phenomenon:

“I said myself all the time that we cannot afford any differing views. [...] To some extent were forced to make decisions by ourselves, we did not have the possibility to get acceptance to everything from everybody. The timeframe was tight and we just needed to get the papers done – we just put a few people to work on them and the core group commented (Heikkonen, 2009).”

The ‘civil war’ amongst DPOs and their leaders was very much affecting the public image of the whole advocacy campaign. Members of the Parliament were blaming the demonstrators that they did not have the legitimacy of the whole disability movement in Finland. This raised a lot of frustration among the demonstrators because they actually had the support of the Finnish disability movement. The diversity and disagreements were solved among the few leaders who started to trust each other.

Every movement has to contend with a “plurality of orientations” (Melucci, 1989 cited in Dowse 2001). The diversity under “PWDs” is very challenging to overcome (Katsui - Kumpuvuori, 2008:234). “Effective leaders” of the disability movement have been widely recognised to move the agenda forward (Foster-Fishman et al. 2007:341). They are central in transforming individuals from passive recipients of discrimination into agents of change (*ibid.* 342). From the above-mentioned cases, we can draw the preliminary conclusion that when an advocacy project is on-going, decisions have to be made quickly. There is no time to negotiate or to get acceptance from the individual members. This has at least a few implications: the leaders in charge need to have strong support from their organisations to withstand the turbulence relating to the advocacy, otherwise they actually lose legitimacy and people can pass over them and invalidate their mandate. Alternatively, collective identity formation among them and maintenance of values have become important today as a form of new social movements (Dowse, 2001:125). Moreover, the core group has to be small enough to enable fast processes in drafting and accepting the

advocacy papers. This is known as “The Law of Michels’, the Iron Law of Oligarchisation” (Michels, 1911 cited in van Houten and Jacobs, 2005). Finally, groups of PWDs that are traditionally in politically strong positions cannot advocate successfully by themselves, allies need to be obtained.

Thirdly, the implementation of the Laws is divided into two types of obligations: moral and binding (Millward et al, 2005). In the Ugandan case, the negative attitude of the society has hardly been changed with this Act. “Some still feel it is the duty of the donors to come in and help (Mwesigye, 2009)” especially when the resources are limited and the resources required for changing a historically discriminatory society and for impairments-specific needs are not small. “More resources” is one of the most important implications (Millward et al, 2005). Hence, negotiation with colleagues has been very challenging. Some district disability councilors managed to plan budgets for disability causes, but many others have little or no resource allocation for any activities for their constituencies with disabilities. Poverty is a great challenge as well as a good excuse for the responsible public agencies not to fulfil their duties as mere moral obligations. As a result, little changes have taken place and they are not even monitored in Uganda (Lule, 2009; Mwesigye, 2009).

In the Finnish case, different municipalities have implemented the personal assistant system to a different extent and created inequality among PWDs living in different places. In a small scale, this has led to “domicile-shopping”, which means that PWDs choose their place of domicile in regard to where they get the best services. That is, in both cases, laws are at times understood as moral obligations with the excuse of resource constraints by of the primary duty-bearers justifying their limited implementation.

All of these challenges are deeply rooted in the local community where PWDs live and cannot be easily changed over a short period of time with enactment of laws. The analysis of these challenges has clarified that law making is important but is more a process rather than a goal in itself. These challenges often affect success and too frequently failure of the implementation of a law to the lives of PWDs in both countries. At the same time, these challenges and structurally rooted causes explain part of the reasons for the disability movement to use both political and legal advocacy for making necessary changes today.

PERSONAL EXPERIENCES AND HUMAN SECURITY

Personal experiences are always involved in any type of self-advocacy. Experiences of PWDs on discrimination are surprisingly similar around the globe, while personal accounts are as important. An interesting phenomenon in both cases was that personal experiences on their advocacy activities were framed very closely to the organisational level and the results of the advocacy project:

“Taking the thing forward was at some points very hectic and also tiring but at the same time also rewarding, because we got

our own goals included to the law. It felt like one could actually make an impact on some issues and that the dialogue with the legislator worked (Keski-Korhonen, 2009).”

“We fought to have a gender balance within the representation. That’s why you see we have one man and one woman at LC-5 and LC-3 [different levels of the local structure]. Those are the districts and sub-counties. Those are the gender rights that we are looking at. Those were the things that we fought for (Nalule, 2008).”

The phenomenon described above has most likely to do with the hectic nature of the advocacy activities. People involved in the core group do not necessary have time to reflect on their own situations and feelings during the activities. This could be very serious because it may endanger the future capabilities of the movements because the members of the core groups are likely to get tired (Akaan-Penttilä, 2009; Lule, 2009). Besides individuals getting tired, this may have an effect of reinforcing the introvert nature of the core group, because they do not have the time to listen to other people. On the other hand, producing a good result from an advocacy activity has tremendous potential in empowering people, which would result in new and better advocacy activities.

Finally, it is necessary to make an important link to the concept of human security and explore its significance in the context of human rights advocacy of DPOs. Human security starts from the recognition that people are the most active participants in determining their well-being (Commission on Human Security, 2003). In these cases, it means that to achieve the highest possible level of human security, PWDs and their organisations need to be the key players in changing society on the issues that concern them. The autonomy is also relevant to the closest persons when PWDs have severe impairments and barriers to communicate with others. Including the closest persons is an important approach particularly in Uganda where individuals belong to a bigger unit such as family, clan or community, which is different from an individualistic approach of Western countries. It is common that when discussing about the realisation of human rights of PWDs, the attention turns to the actions and omissions of the state. Almost as commonly, the state pleads successfully to the lack of resources. The significance of this dialogue in the sphere of international law has little or nothing to do with individuals with disabilities on the ground. The human security of this group of people does not come true.

Human security is not achieved through multiple and complex international human rights protections mechanisms. Achieving human security is not just protecting people but also empowering people to fend for themselves (Commission on Human Security, 2003). Dersso (2008:6) argues further that in achieving human security by empowerment it is critical to enable people to actively defend their freedoms and to develop the capability to address insecurities.



Human security in the context of PWDs and their closest people can come true through self-advocacy activities. “Personal is political” but also vice versa; “political is personal.” Performing advocacy activities, any type of them, is very much about PWDs and their closest people being exposed to the public domain. This has the implication that whatever happens in the public domain, be it a success or a failure, it has a direct effect to the person and to the realisation of his/her human security.

CONCLUDING REMARKS

This article has discussed different dimensions of advocacy activities of DPOs and the connections of those to PWDs in

and differences in utilising different types of advocacy activities. The ways to take an attitude to different types of advocacy activities had naturally its reasons in the particular societal situation in each country-context. Having said this, one could say that while learning from other domains is essential in developing new ways to work, direct assimilation of a type from totally different societal environments will most likely lead to difficulties. For example, very right-conflict-oriented thinking that utilises legal advocacy in the Anglo-American world would not fit in the more consensus-oriented societal atmospheres of Uganda or Finland.



the context of human security, and will be concluded with three observations on this topic.

First, different types of advocacy activities complement each other. Legal, political and any other type of advocacy activities do not work alone very effectively. All types of advocacy are needed to make societal change. A very legally oriented way of acting leaves big gaps on the political sphere, just as a very politically oriented way of acting ignores possibilities of the legal nature. And one can be sure that there are many more types of advocacy that fall only partly or not at all to either of the two aforementioned. The selected cases revealed the clear trend of advocacy activities of DPOs to increasingly incorporate legal advocacy arguments and methods in their political advocacy works.

Second, the comparative discussion implemented in this article is an important one. By exploring two cases of advocacy activities, it managed to tease out similarities

Third, it is easier to make a solid link between empowering PWDs and their organisations, utilising different types of advocacy activities and human security. Human security cannot be realised if PWDs are not given the opportunity to make their own decisions or if their closest persons are not given it, especially when PWDs have severe impairments and barriers to communicate with others. Including the closest persons is an important approach. There are many tools to choose from to go on with advocacy activities or even to decide not to take part in them. The most important implication with regards to achieving human security is the empowerment to make own decisions for oneself.

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