Disability Assessment Mechanisms: Challenges and Issues at Stakes for the Development of Social Policies in light of the United Nations Convention for the Rights of Persons with Disabilities

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Summary Report

1. Object of the study and context

To date, November 2012, the United Nations Convention for the Rights of Persons with Disabilities (CRPD) is signed by 153 States and ratified by 119 of them¹. Its implementation requires that States, among other obligations, ensure disabled people access to a wide range of support measures and services enabling them "to live in the community, with choices equal to others, and [that they] shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community"². But considerable differences exist amongst countries regarding the availability of support services and compensation measures. In all cases, the criteria and access mechanisms to benefits and services, therefore to public resources, are at the heart of current reforms, or developments, of public policies.

The European Forum of Disabled People³, consulted in the context of this study, stresses the importance that organisations of disabled persons (DPOs) attach to reforms, whether these

¹ http://www.un.org/disabilities/countries.asp?navid=12&pid=166 retrieved 05/09/12

² CRDP, article 19.

³ European Disability Forum, Observatory of the crisis http://www.edffeph.org/Page_Generale.asp?DocID=13854&thebloc=28111

aim at revising eligibility criteria to services and benefits, or the overall procedure of disability assessment, at a time when governments announce swingeing cuts in public expenses in the social and medico-social fields⁴. It is also a central question for the World Bank faced with an increasing number of countries who seek assistance "to improve their disability assessment system and disability certification", which leads the World Bank to question which "problems to tackle regarding current systems and how they can be improved" (World Bank, Social Protection and Labor, Strategy 2012-2022).

Paradigm shift

The reform, or the development, of access mechanisms to services and benefits depends on the disability paradigm they are based on.

The United Nations, representatives of disabled persons and DPOs⁵ underline that in a system of provision based on the individual and medical model of disability assessment mechanisms contribute to refer disabled children and adults to special institutions, or to discriminate them in their access to education and employment, inter alia.

Eligibility criteria and model of assessment result from the choice of disability paradigm and from the social and economic context.

In middle- and low-income countries and with high level of poverty who have implemented social protection policies for disabled persons, notably by allocating indemnities or pensions likely to have a substantial impact on the standard of living of the whole household⁶, access mechanism represents a major issue for disabled people's organisations.

In spite of the fact that the international community, working at promoting the rights of disabled persons, stresses the need to develop mechanisms to assess participation restrictions, obstacles and support needs, the necessary reforms are often perceived by policy makers, service providers, international organisations and even DPOs, as complex and costly, with little added value. Current practice, most often based on a medical approach of disability, is considered as complex and costly because of the human, administrative and technical resources it requires, let alone the risks of errors or frauds they bear. Moreover the cost of assessment mechanisms is often an integral part of the budget dedicated to the concerned services and benefits which leads to consider these mechanisms as a necessary burden rather than as a tool enabling to document public policies.

A decision-making tool on eligibility to benefits vs. information system for steering public policies

One of the main and recurrent problems raised by eligibility mechanisms relates to their design and their function. Generally developed after the policies have been designed and set up, whether in the field of education, of family support or allocation of benefits, these mechanisms are mainly intended to manage allocation of resources rather than as information systems.

 $\underline{http://resourcecentre.savethechildren.se/content/library/documents/enabling-reform-why-supportingchildren-disabilities-must-be-heart-success$

⁴ Disability Rights, UK (2012). Disability Living Allowance Reform. http://www.disabilityalliance.org/dlatest.htm

⁵ Better Care Network and Every Child (2012), Enabling reform. Why supporting children with disabilities must be at the heart of successful child care reform

⁶ Johannsmeier, C, (2007), The Social and Economic Effects of the Disability Grant for People with Disabilities and their Households –A Qualitative Study in KwaZulu Natal Province Christa, School of Development Studies, University of Kwazulu-Natal,

http://opendocs.ids.ac.uk/opendocs/bitstream/handle/123456789/1735/RR%2074.pdf?sequence=1

However, to implement the Convention States Parties are required to develop a wide range of services to support participation and inclusion of disabled persons. To this end, they need to develop information systems enabling them to have a better knowledge of the obstacles these persons face, as well as their needs in terms of support.

Given on one hand the unavoidable expenditures for assessing disability and eligibility to services, on the other hand the need for States to have a set of data on the situation of disabled persons, and finally the limits of censuses and surveys, access mechanisms need to be designed so that they generate information usable for monitoring current and future policies, and not only to allocate a certain amount of resources available at a given time. Such mechanisms would contribute to meet the obligation on States "to undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect" to the Convention and "to identify and address the barriers faced by persons with disabilities in exercising their rights." (CRDP, Art. 31).

Developing assessment mechanisms in line with the principles of the Convention and contributing efficiently to its implementation by enabling equitable access to services and devices, themselves compliant with the CRDP is a complex process which supposes to move beyond a number of assumptions, of political interests and budget constraints. In most countries, a majority of stakeholders and actors are in dire need of support to face this complexity. Because a reform can succeed and last only if all the stakeholders understand what is needed, what is at stake and what is the purpose, it is essential that they have methodological tools to help guide the understanding and the analysis of existing systems and their divergences regarding the principles of the Convention.

The aim of this study is to develop an analytical tool to enable the various stakeholders and actors to play an active role in current or coming reform processes.

Structure of the study report

The report, summarized here, is organized in five sections. The first section is dedicated to the conceptual framework, referred to CRDP, and to the issues related to disability assessment mechanisms (Chap.1). The presentation of the methodological approach and of the stages of the study, the questions that have framed the literature review and the analysis of its results compose the second section (Chap. 2 & 3). The third section presents the design of the templates, their description, the field testing in Romania and its results (Chap. 4, 5, 6), the assessment of the outcomes of the focus groups on the templates with DPOs in six middle- and low-income countries (India, Nepal, The Philippines, Rwanda and Tunisia) and the results of the tests carried out in two of these countries (India and The Philippines) (Chap.7). A fourth part provides a complementary analysis of the issues at stake regarding assessment mechanisms from the point of view of the political economy of the disability movement (Chap.8). The fifth part deals with the scientific, conceptual and practical limits of the study in light of the CRDP, draws recommendations from the study and opens new perspectives (Chap. 9, 10, 11).

2. Conceptual framework and issues at stake

The conceptual framework is based on the CRDP. The issue of disability assessment mechanisms and determining eligibility for benefits is intrinsically linked to that of the chosen definition of disability.

The CRDP does not provide a legal definition of disability, but the preamble of the Convention states that "disability is an evolving concept and [that] disability results from the

interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others", confirmed by article 1: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

The CRDP does not provide either specific guidance for developing disability assessment mechanisms or for determining eligibility. However a number of the Convention principles, related to the purpose of these mechanisms, to the assessment of disability and to the process themselves, enable to steer action (namely art.2, § 4).

Moreover by ratifying the Convention, the States Parties commit to ensure access to all services intended for the public on an equal basis with others and to

- "take all appropriate steps to ensure that reasonable accommodation is provided." (art.5.3)
- "ensure persons with disabilities to have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." (art.19.b)
- "ensure access to appropriate and affordable services, devices and other assistance for disability-related needs." (art.28.2.a)
- -"ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses" (art. 28.2.c)
- "provide early and comprehensive information, services and support to children with disabilities and their families" (art. 23.3)
- facilitate "the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost" (art. 20.3)
- facilitate "access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost" (art. 20.b).

In line with the principles and vision of the CRDP, disability assessment mechanisms must concentrate on participation restriction and on support needs of the disabled person more than on her/his impairment or functional limitations. This implies also that these mechanisms take the environment into account, most often overlooked in assessments.

Participation of disabled persons

The Convention is quite explicit that choices and preferences of disabled persons must be respected on an equal basis with others. This applies to different aspects of assessment mechanisms, in particular to the designing of the mechanisms themselves as stated in article 4.3: "States Parties shall closely consult with and actively involve persons with disabilities [...] and their representative organisations", and to the assessment of the person's support needs as well.

This study, carried out in close collaboration with organisations of disabled persons, shows that these core actors often have a very partial understanding of disability assessment mechanisms and of determining eligibility, because they look at them through the lens of their own sectorial specific needs.

What does disability assessment mechanisms mean?

A number of factors must be taken into account in the understanding and analysis of disability assessment mechanisms and determining eligibility:

- the type of approach adopted by the State (a piecemeal or a "one-stop-shop" approach?)
- the purpose of each mechanism

- the different steps and elements taken into account in the procedure framed by each mechanism.

The disability assessment and eligibility to benefits mechanisms vary considerably according to their aims, their functions, their status –public or private— and finally according to their centralisation in a "one-stop-shop" or their fragmentation among different ministerial departements.

Aims: They may aim at ensuring "that services are provided only and exclusively to those who meet tightly specified criteria of eligibility as part of a rationing process of scarce resources" or conversely, they may aim at identifying the needs of the person and target the best match between needs and services. They may also restrict access to a given type of services, such as access to mainstream school for instance by referring the disabled child to special institutions.

Functions: The functions of assessment mechanisms and referring may relate to

- the definition of a status: "disability certificate" giving direct access to benefits or services, tax exemption, etc.
- entitlement to a specific support
- assessment of functional capacity giving access to education, employment
- assessment of support needs
- referral and orientation to services.

Public or private status: Assessment mechanisms may be public, when they apply to measures linked with devices funded by public funds, such as social protection benefits, or private when they apply to access to services provided and funded by non-State actors, which is often the case in middle- and low-income countries.

Models of functioning: Basically, there are two patterns of mechanisms, often combined in reality:

- a structure based on the principle of the "one-stop-shop" ensures both the assessment of the person's needs and access to all compensation devices and benefits provided by the different ministries
- each ministry develops its own assessment mechanism on the basis of which it gives access to specific types of compensation devices and benefits.

The implementation of the CRPD implies to revisit the types of services and benefits intended to support the participation of disabled persons. In many countries this implies therefore to overhaul procedures and mechanisms of disability assessment, and to revise their purposes and their components. The task is particularly complex when the legal framework includes several disability assessment mechanisms, based on different definitions of disability, each of them taking different dimensions of disability into account, and combined with the crucial issue of resources.

This study attempts to design tools, based on the International Classification of Functioning, Disability and Health (ICF, WHO, 2001) following the recommendation of the World Report on Disability (WHO, 2011), to enable actors and stakeholders to analyse existing assessment mechanisms, their purposes, their components and procedures, in light of the CRPD.

3. Methodological approach and literature review

⁷ Bilson, A. & Harwin, J. (2003). Gate keeping services for vulnerable children and families. A concept paper. Unicef. http://www.unicef-irc.org/publications/pdf/gatekeeping.pdf, p.11.

The research team was composed of six complementary skilled persons, with longstanding experience in the field of disability (social scientist, social work trainers, field practitioners and policy analysts with expertise at international level in the field of implementation of CRPD and disability policies aiming at inclusion and social participation of disabled persons). Six 2-days working sessions were held in Brussels in 2011 and 2012 to design and improve the successive drafts of the analytical templates with the feedbacks from the field, the results of the focus groups carried out by two of the researchers in the seven countries selected for the study⁸ and results of the template testing in two of these countries. In parallel, a review of international literature on disability assessment mechanisms, at individual and population levels, was carried out.

4. Guidance templates

The templates are intended for all stakeholders and as such for representatives of authorities responsible for disability assessment with a view to an inclusive approach. These templates are meant to be a guidance tool to collect appropriate information to identify the one or several dimensions taken into account in a process of allocation of benefits (financial or in kind) within a given system. Based on a progressive logic, the templates are built according to the following structure: (1) steps to collect appropriate information linked to the existing procedures; (2) analysis of the mechanisms in the studied system and of their consistency with the rights of disabled persons as stated in the CRPD.

Template 1

Assessment and decision processes for granting a status of disabled person

The first template is meant to identify if in the studied system there exists a legal status of disabled person, as a precondition for the allocation of one (or several) benefit(s) (financial, social, in kind, ...). The template includes a series of 22 questions organised in 6 sections meant to describe the existing procedure:

- 1) legal frame defining the status of disabled person
- 2) accessibility of the procedure
- 3) actual assessment mechanism
- 4) decision-making process
- 5) information centralisation and management
- 6) practical implementation of assessment procedures

To bridge the template with CRPD, a cross-walk table matching each question with relevant CRPD articles is joined to the template, enabling the user to identify the gaps between the existing mechanisms and the CRPD and the recommendations that need to be made to improve the current mechanisms.

Template 2

Sectorial assessment of social participation

The second template is meant to analyse a sectorial approach of assessment mechanisms that determine the allocation of benefits⁹ intended to support social participation in one domain or

⁸ At the October 2011 workshop were invited four representatives of International DPOs (Christian Blind Mission, European Forum of Disabled People, Light for the World and International Disability and development Consortium) with the double aim of consulting on the relevance of the instrument in progress and of sensitizing managerial representatives of key DPOs to the work in progress, with a view to subsequent adoption by the community of disabled people of the results and the tool once validated.

⁹ The term « benefits » is used here as a generic term to designate a financial or in kind benefit, human assistance, tax or legal benefit, access to a private or public service, etc. granted on completion of an assessment that evidences the entitlement or the need of a disabled person to benefit from it to improve one dimension of her/his social participation.

another (access to employment, to education, etc.). The template is composed of a series of 19 questions organised in 5 sections:

- 1) legal frame of the assessment procedure
- 2) accessibility of the assessment procedure for allocating the benefit
- 3) assessment mechanisms for the allocation of the benefit
- 4) decision-making process
- 5) centralisation and management of information

This template is complementary to template #1 when the allocation of benefits is not based only on the status of disabled person, but when the latter is a legal prerequisite giving access to a sectorial process according to the age of the person and the difficulties she/he meets in her/his full social participation on an equal basis with the other members of the community.

This template will be useful also when the current system does not provide for granting a status of disabled person but only for sectorial assessment and benefits allocation mechanisms. When describing the system, the user has to identify the benefits relying on decisions based on the results of an assessment. If the assessment is multidimensional, and if it includes the assessment of participation restrictions and environmental obstacles, the decision-making process should allow for a more efficient allocation of benefits. Conversely, an assessment limited to the only impairments and functional limitations of the persons bears the risk to end up in a uniform allocation system based on a categorization of the disabled population.

Template 3

Process of assessment by benefit

Templates 3 and 4 are optional. They propose complementary analyses to users who wish to get into more detailed examination of the system. Experience shows that some users of the templates and in particular representatives of disabled people engage more easily in the analysis starting from allocated benefits. Template #3 provides the following steps:

- 1) Identifying the population of reference to be examined
 - a. General population of disabled persons
 - b. Population identified in terms of impairments: sensory, motor, cognitive
 - c. Population identified by age
 - d. Population identified according to a geographic criterium
- 2) Identifying existing benefits such as:
 - a. Human assistance
 - b. Assistive devices
 - c. Adaptation for a given activity
 - d. Adaptation of physical environment
 - e. Financial benefit
 - f. Tax advantage
 - g. Legal advantage
 - h. Access to a public or private service
- 3) Describing the 3 following steps of the process:
 - a. Demand: identifying the basic eligibility criteria to the demand and the authorities in charge of determining the admissibility of the demand
 - b. Assessment: Who performs the assessment? Content of the assessment. In this section it is the extent of the assessed dimensions which is investigated, as well as the multidisciplinary nature of the assessment process.
 - c. Decision-making: What are the dimensions taken into account to decide upon the allocation of the benefit? What is the authority taking decision?

Several benefits can be dealt with simultaneously if they are the subject of a single proceeding. It is to the user to regroup them on the template.

An additional series of questions referring to the relevant CRDP articles enables the user to evaluate the quality of the assessment process for allocating benefits meant to improve the participation of disabled persons.

Template 4

Estimated impact of benefits on the participation of disabled persons

This template is intended to initiate discussion on the impact of benefits on the level of social participation of a group of disabled persons.

The first step is to identify the target-group of persons that one intends to enquire, according to:

- impairments (sensory, cognitive, ...)
- socio-demographic variables (sex, age, ...)
- geographical location

- ...

The persons of the target-group are invited to express their perception of the impact of a given benefit on their performance in daily life activities and social roles and to rate this perception on a scale. (The scale and its levels are detailed in the report).

This template allows self-reporting or can be used in an interview, provided that it has been made accessible to all disabled respondents.

Testing of the templates in middle- and low-income countries

Through professional missions of two members of the research team, successives drafts of the templates in progress have been tested by potential users (DPOs, policy makers, civil servants of social affairs administrations) in the 7 middle- and low-income countries selected for the study.

5. Political issues at stake in the adoption of the paradigm shift regarding the definition and the assessment of disability

In the course of the discussion amongst the research team and with DPOs and other national actors, questions have been raised on the feasibility of assessment and eligibility mechanisms that would reflect the actual paradigm shift brought about by the CRDP. Whereas technical assessment tools exist to guide assessments at different levels, it appeared that the main stumbling block had to do with political economy issues amongst the movement of disabled persons, leading to a very restrictive interpretation and use of the data collected on assessment mechanisms. Whereas the templates were dealing with increasing the intelligibility of assessment and entitlement mechanisms, the actors' questions focused principally on who should be considered as disabled and therefore entitled to State support.

In countries with major social inequalities and high level of poverty in the general population, and with very limited public resources, political acceptability of developing support measures is based on the idea of lightening the burden that disability represents, and not on that of supporting the disabled person so that she/he can contribute to the labor market on an equal basis with others. Of course, these political issues impact the way benefits and entitlement criteria are designed.

In many middle- and low-income countries, the political economy of the disability movement is often characterized by a strong competition for limited resources, whether these resources come from the State or from international cooperation.

Therefore debates on the definition of disability are often linked to a more or less explicit competition for access to benefits set up by the States, to which all or part of disabled people may pretend. They are also linked to the very aims of the organisations of disabled people.

Indeed, the selection of the types of disability recognized by national legislations is often the result of a convergence of the medical approach of policy makers and experts and advocacy of DPOs, most often organised by type of impairment. These organisations, whose members are legally entitled to access financial benefits or benefits of other kinds, tend to be particularly careful that the existing definition of disability and criteria for entitlement do not expand because it would endanger the sustainability or the amount of the support they have gained. This leads to the non-recognition of other groups as equally disabled, notably persons with psycho-social impairments, even by the disability movement. Moreover the paradigm shift in the definition and assessment of disability may also lead to review who is severely disabled. Is it the person who has totally lost a physiological or anatomical function or is it a person whose participation is totally restricted by barriers and for whom the level of support needs is very high?

At the heart of these political tensions, lies the lack of confidence of disabled persons and their organisations in the political will of the States and/or in their capacity -resulting in benefits- to really implement the Convention, not necessarily because the States overlook disabled people, but also because they face multiple pressing social and economic issues and that the political cost of doing nothing for disabled people is often lesser than doing nothing for other groups.

At a more local level, there is also a lack of confidence in the institutions. In all the countries of the study, frauds, undue granting of disability cards and corruption sometimes necessary to obtain medical certificates were mentioned.

Reflecting the paradigm shift means also leaving more space to the assessment of the situation of the person and no longer referring only to the impairment which, although restrictive, appears easier to objectify. The fear of complexification, of a more significant weight given to the discretionary power of administrative and medical authorities in decision-making and of increased difficulty to appeal of a decision are among the reasons of the reluctance of disabled persons and parents to a change of disability paradigm.

In the course of discussions with DPOs, the issue of the relevance of reviewing the nature of benefits, in particular the issue of the added value to social participation shows that the paradigm shift can be understood only within the overall vision of the Convention and of what its implementation would mean. Not including barriers to participation and support needs in assessment mechanisms coupled with the weakness of information systems and of the uses of the data deprive public and civil society actors of a real picture of the situation of disabled persons and of their needs; a real picture that could spur a change of their perception.

6. Recommendations and perspectives

The reforms undertaken by many States in the field of disability show that the paradigm shift on which the CRDP is based is gaining ground. The study has allowed to show that these mechanisms, still widely considered as a mean to access benefits in contexts of scarce resources, are far from fulfilling a function of data collection and centralisation, at local level, on the situations and needs of disabled persons and on the main obstacles they face to participate in the various domains of social life.

Recommendations

At the end of the study, these observations lead us to express the following recommendations: 1/ A common effort of the representatives of concerned ministries, DPOs and parents organisations, with the support of the United Nations agencies (ILO, WHO) and NGOs working in the field of disability and development, is needed to define what assessment

mechanisms would be necessary to contribute fully to the implementation of the CRDP. It is essential that these mechanisms are not considered only as a mean to access scarce resources, but more broadly as an appropriate source of information to foster the analysis with a view to reforms to which all stakeholders must have the opportunity to contribute.

- 2/ It would be interesting that stakeholders at international level, with pilot countries, define scenarii of assessment mechanisms in accordance with CRDP.
- 3/ Developing specific training for bodies or persons in charge of assessments, highlighting the necessary paradigm shift and focusing on active participation and social inclusion of disabled persons.
- 4/ Developing a dynamic vision of assessment, including periodical revisions of mechanisms and instruments, according to the needs for support expressed by disabled persons and their representatives.

Perspectives

1/ Promotion of the analytical tool

The current work of the research team will be presented in workshops and national and international events, organised within the professional and scientific networks of the team members (starting December 2012 at the Conference "Implementation of the United convention for the rights of disabled persons: concepts and indicators for inclusive policies" organised by IFRH, EHESP, GIFFOCH, Paris, 6-7 Dec. 2012). We see the promotion of this form of concrete and practical analysis of assessment mecanisms as a collaborative method for networks, DPOs and public authorities in the framework of the overhaul of existing assessment mechanisms or their development.

2/ Development in progress of a training curriculum on social participation of persons in situation of disability, for practitioners and all actors involved in the implementation of the different measures linked to the CDRP.

A Leonardo da Vinci supported project for the development of educational material is on its way (2012-2014) mobilizing the expertise of operators in continuous training from Belgium, France, Romania and Switzerland (GIFFOCH network).

3/ Use of the analytical guidance tool in the frame of national reforms as an instrument for the preparation to reforming assessment mechanisms, under consideration in Romania, and for development of disability policies.

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