



Pathways to inclusive development: How to make disability inclusive practice measurable?

By Lars Wissenbach

Introduction

Approximately 1 billion people – 15 per cent of the world’s population – live with some form of disability; 800 million are estimated to live in developing countries (WHO 2011). With a progressively ageing world population and the emergence of non-communicable diseases in low and middle income countries, the number of persons with disabilities is predicted to further increase. Since the Convention on the Rights of Persons with Disabilities (CRPD) entered into force in 2008, several governments, international donors, and implementing agencies have developed policies and made broad commitments pursuing a common objective: **Disability Inclusive Development.**

The relevance of this objective to social protection is two-fold: On the one hand, social protection can play an important role as enabler and facilitator for inclusion. On the other hand, an inclusive approach to social protection opens new opportunities to address underlying causes of vulnerability and ensure equal access to social protection for all. In 2013, Germany was one of the first countries to adopt an action plan for development cooperation, aiming to make development cooperation inclusive for persons with disabilities.¹ In order to bridge the gap between policies and practice and meet its objectives, measuring disability inclusive practices becomes highly relevant and a pre-condition in order to guarantee the right to social protection for all. However, a grave dearth of measurement approaches and instruments able to support the design, implementation and evaluation of disability inclusive activities mark a severe challenge in those regards. Given diverse definitions, measuring ‘only’ disability already remains a demanding task. The rather complex concept of inclusion adds a further unclearly defined determinant. This paper aims to contrast existing

approaches and potential measurement requirements of disability inclusive development and suggests a further perspective to the current debate.

The structure of the paper is as follows: After referring to models of disability, the concept of inclusion and the CRPD as a basis for measurement approaches in part I, part II describes different dimensions of measurement and addresses common approaches, relevant to disability inclusive development. Part III finally discusses a suggested approach to measure disability inclusive practice in programmes or projects.

Models of Disability - a paradigm shift

Disability is a complex construct and a rather vague concept in terms of definition and measurement. Various conceptual models of disability have been developed in the past describing disability from numerous perspectives.

The medical model defines disability from a strictly natural scientific perspective, focusing on impairment and limitations in functioning deviating from ‘the norm’ and requiring rehabilitation and compensation in order to bring a person back or close to what is considered as ‘normal’. No distinction is made between a person’s impairment and disability.

The social model of disability emerged in the 1970s and was strongly promoted by the disability movement, aiming to achieve equal opportunities for persons with disabilities. It fundamentally differs from the medical model by distinguishing between ‘impairment’ and ‘disability’. Disability is not perceived as a result of functional limitations, but rather caused by various disabling attitudinal and environmental barriers which in interaction with impairments impede participation in society and consequently require social

¹ Action Plan for the Inclusion of Persons with Disabilities (2013-2015) launched by the German Federal Ministry for Economic Cooperation and Development in February 2013

change. There are different versions of the social model², and it is widely recognized that no single model can totally explain disability. Each disability model may bring a useful perspective on disability in a given context (Mitra 2006). The so called ‘oppressed minority model’, for example, reveals sensory, attitudinal, cognitive, physical and economic barriers causing discrimination and segregation of persons with disabilities. With reference to Sen’s capability approach (1999), disability can be understood as a deprivation of practical opportunities for persons with disabilities. Such deprivation may result from the interaction between the resources available to the person, personal characteristics like impairment, age or gender, and the environmental barriers (physical, social, cultural, political, and economic) (Mitra 2013).

Looking at disability from such perspective easily leads to WHO’s **International Classification of Functioning (ICF)**, viewing disability as the outcome of dynamic interactions between a person with a medical condition, activities in which that person participates, factors within the environment which hinder or facilitate participation, and overall wellbeing (WHO 2001). Linking the medical and the social model of disability, the ICF adheres to a bio-psychosocial model, viewing health from biological, individual and socio-cultural perspectives (Goujon et al. 2013). Albeit not free of criticism, this comprehensive approach and the worldwide scope of this model strengthened its role as a basis for measurement approaches over the past years.

The concept of inclusion

‘Inclusion matters’. This is the clear message of a recent World Bank Group report (World Bank 2013), promoting social inclusion as the foundation for shared prosperity. The report highlights the potential of inclusive approaches beyond poverty analysis, drawing back the curtain on exclusive structures, practices, norms and belief systems to make the underlying causes of inequalities, poverty and social exclusion visible. Giving a comprehensive review of social inclusion in various contexts, the report defines social inclusion as the ‘process of improving the ability, opportunity, and dignity of people, disadvantaged on the basis of their identity, to take part in society’ (World Bank 2013). However, the profile of inclusion has to be raised in order to furnish policy makers and practitioners setting out towards disability inclusive development.

The concept of inclusion is often used in close relation to the concept of exclusion, defined as a means to combat exclusion and a process to create a ‘society for all’ (Atkinson/Malier 2010). The political exclusion/inclusion discourse is rooted in the policy discourse in France in the



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1960s - originally defined in terms of the ‘rapture of social bonds’ and applied to social disintegration in the context of extreme poverty and slum dwellers. In the 1970s, the term ‘the excluded’ was used referring to persons with disabilities, substance abusers, juvenile delinquents, and marginalized groups whose conditions excluded them from the then incomplete social insurance coverage. Later the concept was adopted by the European Union (EU) and became more and more popular due to its multiple applications in terms of the crisis of the welfare state and growing social challenges including a growing complexity of social groups in the early 1980s. After the World Summit for Social Development in Copenhagen 1995 it spread beyond the EU and was widely adopted by international institutes and organizations, development agencies and the development discourse in general as another way of understanding and reducing poverty (Silver 2010).

With its increasing popularity in the following years, the concept of inclusion was frequently redefined resulting in a varied meaning with various interpretations linked to regional or group specific contexts, often conceptualized as the opposite of exclusion. Cameron (2006) argues that due to a lack of clear definition of the constitution of inclusion, the attention often focuses on the challenges of ‘the excluded’. Such a bipolar view has its limitations due to the fact that individual and groups can be excluded in one domain and included in another, as there is no single centre of society, but various functional subsystems within a society. It leads to an emphasis on barriers rather than determinants that may increase a person’s social inclusion.

Nevertheless, functioning as a normative objective for the full and effective participation of all persons on an equal basis with others, the term is increasingly used at all political levels. Against this background, inclusion is at risk of being mere ideological rhetoric, an aspiration that lacks targets and practical application and requires resources (Cobigo et al. 2012). In order to realise the practical value of the concept and facilitate valid approaches, it is critically important to make disability inclusive development measurable on process level. Therefore it is imperative to leave behind the exclusion/inclusion dualism and build upon a positive and sharply defined approach focusing on the determinants which promote inclusion within development processes and thus build the basis for measuring inclusion on process level.

² a) the Social Model of the United Kingdom, b) the oppressed minority model, c) the social constructionist version of the United States, d) the impairment version, e) the independent living version, f) the postmodern version, g) the continuum version, h) the human variation version, i) the discrimination version (see Mitra 2006)

The Convention on the Rights of Persons with Disabilities – Innovative and normative guideline

The CRPD marks a milestone in disability politics by applying a human rights-based approach to disability and claiming an accessible and inclusive society for all. Therefore it sets out obligations and holds the potential to serve as a guideline for state parties as well as setting a basis for claim for its citizens. It is the first international human rights treaty which obliges state parties to ensure that international cooperation and development programmes are inclusive and accessible for persons with disabilities (art 32). Recognizing inclusion as a general principle (art. 3), an obligation and a right, the CRPD provides a clearly defined framework for disability inclusive development. It reflects a shift from regarding persons with disabilities as recipients of charity, medical treatment and special services towards defining disability as an ‘evolving concept, resulting from the interaction between impairments and attitudinal and environment barriers that hinders their full and effective participation in society on an equal basis with others’ (CRPD: Preamble). Against this background, social protection is a key determinant in order to guarantee the realization of basic civil and political rights for persons with disabilities. Social protection services can serve as instrument to dismantle barriers excluding persons with disability from full and effective participation, for example through covering extra costs of assistive devices or assistance services regardless of income (see e.g. Fritz 2011).

The innovative potential of the Convention results from its activating character. As the adjudication of equal civil and political rights can only become effective if social prerequisites provide the opportunity to exercise those rights, it fails its objective when societal barriers prevent individuals from exercising those rights. The CRPD is pervaded by the indissoluble link between formal rights and essential prerequisites, and it explicitly calls for positive measures (e.g. accessible formats) to ensure that obstacles and barriers excluding persons from exercising their rights can be overcome.

A progressive **realization of the CRPD in the field of international cooperation** is strongly dependent on the measurability of disability inclusive development on different levels. In recent years, the CRPD served as first hand resource for a vast amount of grey literature, manuals and guidelines for inclusive programme designs providing qualitative support to set out towards disability inclusive development.³ Moreover, the concept of inclusion has been concretized in numerous action plans from international to community level in order to realize the obligations of the CRPD.

In 2013, the German Federal Ministry for Economic Cooperation and Development launched an **Action Plan for the Inclusion of Persons with Disabilities (2013-2015)**. This plan is based on the so-called twin-track approach: On the one hand, specific support is intended to empower persons with disabilities and their organizations. On the other hand,

the action plan aims to mainstream the issue of inclusion across the board in all development measures (BMZ 2013). The gradual inclusive design of projects and programmes, according guidelines, the provision of scientifically collated data, and the devise of an approach to record the inclusive design of development measures are central elements of the plan. As the latter holds the potential of making disability inclusive development tangible, it forms a crucial future challenge. While specific measures are much more concrete, measures on the mainstreaming track are often characterized by a rather vague wording, especially in terms of planning and measuring. Therefore, measuring disability inclusion on process level within programmes and projects becomes a major future challenge in order to meet the requirements of the mainstream track and consequently to realize disability inclusion in development practice. The recent call of the report of the High Level Panel on post-2015 to ‘Leave No One Behind’ and being denied basic economic opportunities and human rights explicitly addresses disability (UN 2013). This clearly underlines the urgent need for adequate measurement tools to facilitate disability inclusive practice.

Measuring disability inclusive development – a threefold focus

Measuring the prevalence of disability is imperative for disability inclusive development. Of equal importance is the capacity to assess the quality of life, awareness of rights, protection of disability rights, and community participation by persons with disabilities.

Mont (2007) identifies three major purposes for collecting data on disability:

- a) Monitoring the level of functioning in a population**, understanding the scope of persons with disabilities, types of disabilities, needs and requirements in a population in order to design, inter alia, interventions to prevent or minimize physical and cognitive limitations in functioning, activity limitations, and participation restrictions.
- b) Designing service provisions**, specifically for persons with disabilities or more inclusive general services
- c) Assessing the equalization of opportunities**, aiming to improve participation, reduce poverty and comply with international standards

In the past years, various approaches and tools have been developed to capture those purposes. These approaches may be distinguished in ‘impairment screens’ and ‘functioning screens’ (Palmer 2012).

‘**Impairment screens**’, based on self-identification (e.g. ‘do you have a disability?’) and diagnosable conditions (e.g. ‘do you have a hearing, speech, visual, mobility, and mental disability?’) usually provide the lowest prevalence rates due to negative connotations, stigma or different cultural standards of what is considered as disability. In addition, the effects of a diagnosable condition often depend on external factors like medical treatment, assistive devices, assistance

³ See e.g. CBM (2012), Light for the World (2012), Handicap International (2011), World Vision (2010), World Bank (2006)

services or the accessibility of the living environment. Impairment screens are criticized for neglecting the impact of impairment on a person's functioning in terms of activities or social participation, and the impact of personal or environmental factors (Mont 2007).

'Functioning screens' measure the loss of functional capacity resulting from a health condition. Referring to the ICF this encompasses the domains of body function, as well as activities and participation. As each domain of the ICF concept represents a different area of measurement, this opens possibilities for a great variety of measures at or within these domains. Palmer emphasizes that activities represent parts of participation and can determine mechanisms that interfere with or facilitate participation. By contrast, measuring participation alone does not allow distinguishing persons with impairments who live in accessible and enabling environments from persons without disabilities. Functioning screens generally provide much higher prevalence rates (Palmer 2011).

Currently, numerous approaches and instruments, which measure disability based on the ICF concept, and several scales have been developed to assess the quality of life or participation of both persons with and without disabilities. However, the availability of high quality, internationally comparable data on disability is still scarce (Mont 2007). A recent review of measurement instruments by Goujon et al. (2013) showed that even if existing measurement instruments are of value within their initial contexts of intention, none of those instruments both encompasses the ICF in terms of domains and definition of disability, nor has the capacity to measure disability inclusive practice within development programmes.

The following threefold focus addresses common approaches and submits an additional focus for discussion, emphasizing the measurement of inclusive practice within development processes.

Focus I - Measuring disability prevalence

The variety of disability definitions and measurement purposes and approaches outlined above is clearly reflected in available disability data from across the globe. Disability prevalence usually varies widely both across and within countries. The Australian Bureau of Statistics reported a disability prevalence rate of 18.5 percent⁴ for Australia while the Cambodian Socio-Economic Survey (CSES) states a disability rate of 4.7 percent⁵. The disability prevalence of the Cook Islands was reported to be 0.7 percent⁶ only.

⁴ Survey of Disability, Ageing and Carers (SDAC) 2009, Australian Bureau of Statistics

⁵ Cambodia Socio-Economic Survey (CSES) 2004, National Institute of Statistics, Ministry of Planning, Cambodia

⁶ UNESCAP (2012): Disability at a Glance: a Profile of 28 Countries and Areas in Asia and the Pacific http://www.vision2020australia.org.au/uploads/resource/47/disability_at_a_glance.pdf (last visited Apr. 1, 2014)

While the lack of reliable, valid and internationally comparable data may partly be a result of the great variety of existing disability definitions, the cause seems to be multilayered. Different methodologies, survey designs, data sources (e.g. register / census / disability survey), and collection methods (e.g. self-report vs. objective observation) can lead to fundamentally different outcomes. Specific disability surveys usually report higher rates of prevalence than general censuses due to their more detailed questions. But, it is of importance that disability prevalence can be measured via censuses because separate surveys are often too expensive especially for low income countries (Mont 2007). Goujon et al. (2013) emphasize that countries generally underreport disability prevalence and the needs of persons with disabilities. This weakens the ability of stakeholders to design appropriate and evidence informed programmes, and to measure the effectiveness of respective interventions. Most recently the High Level Panel on post-2015 report called for a 'data revolution' including data disaggregated by disability which at least offers the prospect of supplementing census data on disability (UN 2013). Due to a variety of purposes, measuring disability prevalence - if based on a functioning screen perspective - is challenging. Measures always have to ascertain which component of the ICF best reflects the information needed to address the purpose of the respective data collection (Mont 2007). Some of the most commonly used approaches and tools are briefly addressed in the following sections.

The Washington Group questionnaire on disability (WG questionnaire) was developed by a City Group⁷ sponsored by the United Nations (UN) and authorized by the UN statistical Commission in 2002 to improve the quality and international comparability of disability measurement in censuses and to provide comparable data across national, cultural and age related aspects. The instrument consists of a short set of 6 questions⁸ for census purposes to assess prevalence of limitations in functioning in six basic actions: seeing, hearing, walking, cognition, self-care, and communication. The questions have been used in the World Health Survey and the instrument has marked a major step forward in recommending a simple set of internationally-comparable questions (Samman 2013). These questions can address the 'equalization of opportunities' purpose by comparing limitation to employment level, income, education etc. and thus can provide evidence on opportunities of persons with disabilities to be included in social and economic life (Mont 2007). However, these questions seek information about functional capacity (without covering psychological limitations) rather than participation and environmental factors. Hence, different from the ICF definition of disability and the social model, they do not draw a comprehensive picture of disability.

The WHO Disability Assessment Schedule 2.0 (*WHO DAS 2.0*), developed by the World Health Organization (WHO), aims to provide a single generic instrument for assessing health and disability levels across different cultures and settings. It was designed to measure the difference

⁷ <http://unstats.un.org/unsd/methods/citygroup/> (last visited Apr. 1, 2014)

⁸ There is also a long set with 27 additional questions

made by a given intervention, achieved by assessing the same individual before and after the intervention. The interview based stand-alone tool captures the level of functioning in six domains of life: cognition (understanding and communicating), mobility (moving and getting around), self-care (attending to one's hygiene, dressing, eating and staying alone), getting along (interacting with other people), life activities (domestic responsibilities, leisure, work and school), and participation (joining in community activities, participating in society). While integrating an individual's level of functioning in major life domains and directly corresponding with the ICF's activity and participation dimensions, it does not capture the impact of environmental factors on life (WHO 2013).

The Model Disability Survey (MDS) is a new initiative currently carried out by the WHO and the World Bank to collect comprehensive and relevant information that helps countries drawing a complete picture of disability with particular relevance to disability policy and services, and to monitor progress in the implementation of the CRPD in their respective countries. It is planned to be a stand-alone survey, but will potentially include a core questionnaire that could be incorporated in general surveys. Survey questions aim to gather information both on the limitations in the capacity to function as well as the features of the environment that facilitate or create barriers to functioning.⁹ Such initiative follows the recommendations of the World Report on Disability (WHO/World Bank 2011).

The effectiveness of all tools above depends on the purpose of their application. All of them are of value within their initial contexts of intention and have strengths and weaknesses. It is still difficult to achieve comparability of data across countries, cultures and settings. With the CRPD internationally in force and with a call at international level for the explicit inclusion of persons with disabilities and adequate disaggregation of data, the availability of reliable data is more than ever needed and crucial to inform policy and programme development to be disability inclusive.

Focus II - Measuring participation and quality of life of different population groups

Measuring participation or quality of life is different from assessing disability in the sense that it focuses on the impact level of inclusive development activities and thus explicitly implies environmental factors. The need for full and effective participation in society of persons with disabilities is emphasized by the CRPD. In recent years, several significant initiatives to measure societal progress more comprehensively incorporated subjective reports of well-being (World Bank 2013). Participation is considered a key factor for quality of life. At the same time, both the level of participation and quality of life can serve as indicators on the impact dimension of disability inclusive development.

The Participation Scale aims to measure social participation by persons with a health condition for use in rehabilitation, stigma reduction and social integration programmes across countries and cultures. Scale development studies were carried out in Nepal, India and Brazil in 1999. A stand-

alone survey of 18 to 36 questions using a peer comparison concept addresses activities and participation domains as defined in the ICF and includes an assessment of discrimination resulting from perceived stigma (van Brakel 2006). The scale is based on a client perception perspective in order to recognize the fact that people with similar health conditions may experience very different levels of participation restriction. The scale may be used as an evaluation and research tool to study participation and the effects of programmes to promote participation.

The Active Limitation Scale (ALS) and Participation Restriction Score (PRS) have been developed from disability surveys in several African countries and are based on the ICF and the social model of disability (see e.g. SINTEF 2009). The ALS represents more basic activities, whilst the PRS covers those to be considered more complex (e.g. self-care, school, work, social and civic life) in order to reduce the degree of counting basic activities that are part of some complex activities as well as to examine the relationship between these two dimensions. The latter holds the potential to explore the extent to which environmental conditions turn functional limitations into disability. Changes over a period of time may allow drawing conclusions on change of environmental conditions. Environmental factors themselves are not specifically addressed in both scales. Mont & Loeb (2008) propose these measures for assessing the impact of interventions on the lives of persons with disabilities and emphasize their importance for the implementation of the CRPD.

Quality of Life (QOL) is a social construct involving community, social and family concepts, including health. An emerging debate on quality of life is routed in the assumption, that personal, family, community, and societal well-being do not only emerge from scientific, medical and technological advances but rather from a complex combination of these advances plus values, perceptions, and environmental conditions (Schalock et al. 2002: 1). Over the last three decades QOL has evolved from a concept to a measurable construct. Its use in programme planning and evaluation is increasingly being discussed, in particular in relation to the quality of individualized supports and services for persons with intellectual and developmental disabilities within inclusive environments (see: Schalock et al. 2008). QOL is a relevant outcome for health and social policies and practices. This view is clearly reflected in WHO's work on the measurement of QOL, aiming to develop an international cross-culturally, comparable quality of life assessment instrument, assessing the individual's perceptions in the context of their culture and value systems, and their personal goals, standards and concerns.

The WHO Quality of Life instruments were developed in the early 1990s collaboratively in a number of centres worldwide, and have been widely field-tested. The WHO Quality of Life (WHOQOL1) instrument assesses subjective wellbeing in different areas of life. While the above mentioned WHODAS 2.0 measures objective performances in a given life domain, these instruments focus on subjective well-being and a feeling of satisfaction about a person's performance in a given life domain (WHO 2010). The WHOQOL-BREF is a shorter version that may be used in large research studies or clinical trials. It comprises 26 items, which assess the following broad domains: physical health,

⁹http://www.southampton.ac.uk/psychology/research/projects/model_disability_survey.page

psychological health, social relationships, and environment. The instrument has been extensively used to both assess QOL and as a reference instrument to validate the outcome of interventions across different cultures and ages. The instrument covers some of the ICF domains, but is not designed to measure disability prevalence (Goujon et al. 2013).

Contrary to the WHOQOL, the **Rapid Assessment of Disability (RAD)** instrument is directed to practitioners to determine disability prevalence within a target population and to design and evaluate the effectiveness of disability inclusive activities in addressing their priorities. Funded by former AusAID the instrument was developed by collaboration between the University of Melbourne's Nossal Institute for Global Health and the Centre for Eye Research Australia. Being a stand-alone survey which was field-tested in a study in Bangladesh, the RAD seeks to support the monitoring of a population's progress towards achieving the disability inclusive goals of the CRPD. The instrument includes questions related to socio-economic factors, assessment of functioning to determine disability prevalence, wellbeing and quality of life, awareness of the rights of persons with disabilities, as well as barriers and facilitators to participation of persons with disabilities within their community.

Focus III - Measuring inclusive practice in development processes

Against this background, a further dimension of measurement in the context of disability inclusive development seems to be of increasing importance, especially for development practitioners. Assuming that inclusion is understood as a process of development, questions arise as to where to start and what to aim at. Besides measuring disability prevalence as a baseline for action and participation or quality of life on the impact level, a certain benchmark is required to capture disability inclusive practice on process level. A corresponding approach needs to prominently indicate the development stage of inclusive orientation within development processes by focussing on key determinants of inclusion, hereafter referred to as 'drivers of inclusion' or simply 'drivers'.

'The real test of moving toward social inclusion is to ask why certain outcomes obtain for certain groups and to **focus on the drivers** and processes of social inclusion' (World Bank 2013). Drivers of inclusion are key determinants in a development process which contribute to shape a process inclusively (e.g. 'participation'). Only in combination and interdependently, different drivers lead to inclusive projects. The identification of drivers for disability inclusive development seems useful in order to develop a comparable benchmarking for inclusion in process. This third focus aims to suggest an approach to measure the level of disability inclusive practice within development programmes or projects based on such drivers.

Understanding the transfer of the theoretical concept of inclusion into practice as a process of adopting a new innovation, key elements of the 'Diffusion of Innovations Theory' (Rogers 2003) shall give a theoretical frame for the driver approach. This idea will be outlined in the following section.

- **Inclusion is an innovation.** For several reasons, inclusion has the characteristics of an innovation, especially in the field of development cooperation. It is a theoretical concept which has to become adaptive for practice, context-sensitive and without blueprints. It is perceived as new and promoted through a sense of need. The process of adoption is a process of change which requires persuasion and strategic decisions while facing the obstacle of uncertainty among stakeholders.

- **Inclusion is implemented by a process of diffusion.** According to Rogers (2003), diffusion happens in an 'innovation-decision process' of five steps: a) raising awareness and practical knowledge; b) persuasion: shaping attitude; c) decision: adoption or rejection; d) implementation: including reinvention / adaption to context; and e) confirmation.

Figure 1: Innovation-Decision Process



- **Inclusion becomes a practical reality by reinvention.** Reinvention - as part of the implementation - describes 'the degree to which an innovation is changed or modified by a user in the process of its adoption and implementation' (Rogers, 2003). It is the adaptation of the socio-economic condition and institutional framework of a respective programme or project – the process of using the new concept which creates ownership.

From a measurement perspective, the status of this process of diffusion and (if a decision has already been made) the process of reinvention can provide the required information on the inclusive orientation and inclusive practice within development projects and programmes.

- **Inclusion is reinforced through drivers.** As such processes do not run automatically, it is the drivers which actively run the process of diffusion. Even decision does not guarantee implementation and confirmation as it can be reversed if not supported through various drivers. Against this background, the drivers and their characteristics make disability inclusive development tangible within programmes and projects and consequently provide a basis for process indicators.

In practical terms, such project indicators become most relevant with respect to monitoring and evaluation of action plans on disability inclusive development. As outlined above, the often rather vague wording of measures on the mainstreaming track of the twin-track approach is a major challenge in terms of measurement. For example: '[...] the inclusion of persons with disabilities will be systematically ensured in the priority area 'health' (BMZ 2013). When inclusion is 'systematically ensured', what do we have to aim for? Whereas it is possible to measure outputs of such activities, it remains challenging to assess progress of inclusion within the process. However, the drivers – once defined – hold the potential to be tangible variables and a basis for process indicators.

From theory to practice – drivers of inclusion in development processes

Identifying a set of drivers

Based on the theoretical frame outlined above, drivers have been identified from key aspects of the CRPD, various guidelines for inclusive project design, practical experiences in striving for inclusive development as well as by a review of existing definitions for inclusion and extraction of their core elements. The following suggested drivers play a crucial role within the diffusion process of inclusion.

Participation of persons with disabilities and their representative organizations raises the quality of the process of reinvention through different perspectives and promotes acceptance for change.

Promoters are key-actors in decision making, running development processes and motivating others to get engaged in the process. They are crucial change agents for the processes of persuasion, decision and reinvention

Awareness draws on the diffusion of a social and human-rights-based understanding to disability, participation and inclusion among all stakeholders and creates acceptance for the need of change.

Accessibility for all people, beyond its physical aspects, is one precondition of participation. This does also include barrier-free information and communication.

Structural integration refers to the embodiment of inclusion within the policies and institutional structures of an organization, programme or project and is thus a core characteristic of reinvention and confirmation.

Positive political and legal framing through legislation, policies, and action plans on different levels make innovations consistent with existing values, objectives and needs.

Resources are a crucial aspect at the decision and implementation stage, as costs could be perceived as disadvantage. If not considered adequately, a lack of resources can lower the quality of implementation.

Data on disability prevalence, on the life-realities of persons with disabilities as well as on disabling barriers is relevant prior to the decision process in order to raise knowledge and awareness as well as for the quality of implementation. Furthermore it contributes to decreasing complexity.

Qualifying the drivers

Each of these drivers is distinguished by its individual dimension of quality which creates a basis for indicator development. In order to illustrate this dimension, the following lines will address two of these eight drivers more closely and will discuss qualitative aspects related to them.

► **Participation**, as a key driver for disability inclusive development, represents self-determination of persons with disabilities and their families and is therefore one of the drivers. Various models of social and political participation have been developed over the past decades to describe levels of participation ranging from information to consultation, and to the levels of partnership and citizen control (see e.g. Arnstein 1969).

In addition, there are other quality aspects of participation. Participation can happen sporadically or be structurally embedded. There can be temporary consultations of different stakeholders or a regular exchange with for example Disabled People's Organizations; depending on individual decisions or institutionalized in strategy papers, monitoring instruments, action plans etc. Participation can be understood as an add-on activity or be a part of the culture and a quality feature. This is closely related to the awareness of the added value of participation. Options of participation can be limited through financial restrictions or be equipped with adequate resources. A part of the budget can be reserved for this type of investment at the project planning stage. Participation generally goes together with accessibility. Accessible formats of information and communication (e.g. easy language, sign language, braille information) can be accompanied by empowerment to participate. All these characteristics can serve as a platform to develop context-specific indicators for the driver of participation.

As the diffusion of an innovation like inclusion moreover always stands for change, conflict due to contradictory interests is a natural and necessary component of such process. Participation is a means to bring these interests into dialogue and increase commitment to the change process.

► **Promoters** are key-actors who take decision in favour of inclusion, actively run development processes and thus highly promote and give face to the cause. Promoters make disability inclusive development visible, popular and allow identification with the cause.

Different types of promoters exist. There can be promoters of power (hierarchical legitimized, leverage, financial resources, authority to overcome motivation-barriers and hierarchical barriers), professional promoters (knowledge in subject and methods, skills to overcome knowledge barriers), process promoters (organizational knowledge, ability to communicate), and relationship promoters (network-knowledge, cooperation between relevant stakeholders) (Witte 1973, Hauschildt 2004).

More than just one of each promoter type can be identified in a project. Different types of promoters can even be combined within the same person. Promoters might be more or less active in their role and have various motivations to play their role. How sustainable they are in their capacity as promoters depends on various factors, such as the integrity of the persons, the acceptability of the person by the population, their political participation etc.

Indicators can be developed on the occurrence and number of the different types of promoters within a project and the level of their respective activity and sustainability.

Promoters can promote and reinforce the reinvention of inclusion by the stakeholders. Furthermore they can reduce the degree of uncertainty which can be a major barrier within the process of persuasion, decision and implementation.

Key aspects for indicator development

If we look at the quality of the drivers, we can derive certain possibilities for indicator development. Each driver serves as a parameter for a different element of inclusion. The combination of these drivers makes inclusion tangible within a programme or project. A set of elaborated drivers

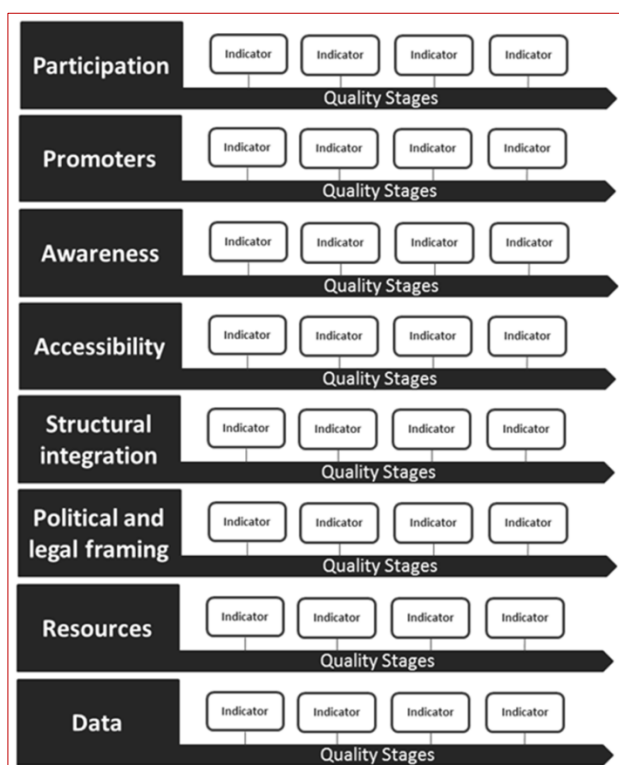
opens the opportunity to measure the level of inclusive orientation or inclusive practice within a programme or project.

It follows from the above, that indicators for the diffusion of inclusion in development processes can be developed on the basis of:

- a) the **number** of different ‘drivers of inclusion’ apparent within a process
- b) the **qualitative dimension** of each ‘driver of inclusion’

Hence, the diffusion of inclusion becomes a practical reality both by the availability and the qualitative occurrence of the drivers.

Figure 2: Drivers



The drivers are closely interlinked. The examples of participation and promoters clearly show this interaction at several points. For example, participation of vulnerable groups may be linked to awareness raising and attitudes, structural integration, accessibility of its formats or even the knowledge about relevant stakeholders and their interests.

The drivers do not develop coincidentally but can be activated and actively developed through consulting, empowerment, capacity development etc. They also open a framework for planning processes. The identified level of quality for each driver and the set of drivers as a whole offer guidance for planning. Consequently, the envisaged approach does not aim to focus on a pre-defined point of reference certifying a process to be inclusive or not inclusive, but rather to create a scale or an index to level inclusive practice in a project or programme. Hence, it holds the potential to assess baseline data and progress on inclusive practice while at the same time giving advice for planning progress through phased targets.

When applied to the project cycle, a set of elaborated drivers can provide a basis for a methodological tool (e.g. an index), which will be able to measure disability inclusive practice and cope with the required instrument filling the gap between the measurement of disability prevalence and achievements on the impact level.

The way forward

In recent years, the innovative concept of inclusion evolved to be a highly promising approach to combat poverty, promote equal access to basic civil and political rights and raise the quality and sustainability of international cooperation.

Several governments, international donors, and implementing agencies have developed policies and made broad commitments. However, bridging the gap between policy and practice remains a challenging task toward disability inclusive development.

Based on the ICF definition of disability, the Convention on the Rights of Persons with Disabilities qualifies the concept of inclusion even beyond disability and provides a clearly defined framework for disability inclusive development. Translating its obligations into practice requires a measurement approach which - applied to the project cycle - will be able to measure disability inclusive practice. Such an approach is meant to complement existing measurement activities on disability prevalence as well as participation and quality of life measures on the impact level.

Measuring inclusive practice implies looking at a comparable set of aspects. From a development perspective we propose the idea of drivers for developing a benchmarking to make inclusion tangible within programmes and projects. The rationale being that it is these drivers which provide a platform for indicator development.

The diffusion of innovations theory provides a theoretical framework to further develop this approach. The added value of a measurement tool based on this approach has various facets. As each driver serves as a parameter for a different element of inclusion, it offers phases for a clearly structured planning process, while at the same time enabling baseline and process measurement.

In order to enhance the ability of development stakeholders to design appropriate and evidence informed programmes and projects and to measure the effectiveness of interventions aiming towards disability inclusive development, there is a need for a multi-layered measurement debate. In the light of different purposes of collecting data on disability and a great variety of measurement possibilities on different domains of disability inclusive development, a single approach seems neither feasible nor constructive. Each of the addressed focuses provides crucial evidence to strengthen disability inclusive development. While there is much debate on measuring disability-prevalence or inclusive impact, equal attention should be given to measuring inclusive practice in progress.

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The paper is intended to contribute to the debate and offers an overview of the current international discourse and more profound insights into current practice.

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