Technical Guidance Note Social Protection and Disability 2014

1 Executive Summary

Australia's aid program is supporting initiatives that provide regular and predictable cash or in-kind transfers to individuals, households and communities in our partner countries. These social protection programs aim to reduce poverty and vulnerability, and to foster resilience and empowerment. This guideline will assist staff to better understand why and how to include and/or target people with disability in these social protection programs. Approximately 15 per cent of the world's population has a disability, and this is expected to increase in the future with population ageing and increases in chronic health conditions associated with impairment and disability. There is a clear link between poverty and disability, which means that our aid program needs to consider disability in our social protection work.

This guideline provides an overview of key issues to consider when designing, implementing and reviewing social protection programs to ensure people with disability are included in and benefit on an equal basis with others. It provides 10 key actions staff can take to consider and implement disability-inclusion in the design, implementation and review of social protection programs:

- 1. Begin to **increase your own awareness** about the situation for people with disability and their families in the proposed program location. Consider barriers that may be faced by people with disability in participating or benefiting from a proposed program, giving particular consideration to the different needs of women, men, girls and boys with disability.
- 2. If you are determining a budget for a program design phase, include budget provision for consultation with people with disability and analysis.
- 3. Consider what additional analysis (if any) will be needed in the design phase, and commission dedicated analysis on the barriers and opportunities for people with disability and their families to be included in and benefit from both disability-specific and mainstream social protection programs.
- 4. **Consult with people with disability** during the design to help you identify relevant issues.
- 5. Ensure the design of social protection programs **considers issues of disability classification**, **targeting and eligibility** as well as benefit level and type.
- 6. Work with implementing partners to make **informed design decisions** on adaptations and/or new initiatives for either/both disability-specific and mainstream social protection programs.
- 7. Support the inclusion of disabled people's organisations (DPOs) and government institutions with responsibility for disability in regular **governance and coordination mechanisms** for social protection programs at all levels (national and sub-national). Ensure these organisations have sufficient capacity to engage in a meaningful way in these mechanisms.
- 8. **Ensure disability is made explicit in reviews** of social protection programs. Include an explicit question in the Terms of Reference for reviews, along the lines of "Were people with disability included in and able to benefit from this program? How? To what extent?"
- 9. **Facilitate involvement of disabled people's organisations** in regular formal, informal, qualitative / quantitative monitoring and evaluative processes for all social protection programs.
- 10. Pay particular attention to issues around **disability classification and targeting** during implementation and review.

2 Table of Contents

1	Executive Summary	1
2	Acronyms	3
3	Context: Understanding Disability, Poverty and Social Pr	otection
		4
3.1	Understanding Disability	4
3.2	Disability and Poverty	5
3.3	Definition of Social Protection	7
3.4	Disability and Social Protection Programs	7
4	The Social Protection Program Cycle: Key Issues to consdisability-inclusion	sider for 10
4.1	Design	10
4.2	Implementation and Review	16
5	Summary: What you can do	18
5.1	Design	18
5.2	Implementation and Review	18
An	nex 1 Washington Group Short Set of Six Questions	19
An	nex 2 The Ten Question Screen	21

3 Acronyms

BPC	Beneficio de Prestacao Continuada (which is Brazil's Continuous Cash Benefit program)
CRPD	Convention on the Rights of Persons with Disabilities
DAS	Disability Assessment Schedule
DPO	Disabled People's Organisation
DSWD	Department of Social Welfare and Development (Philippines)
ICF	International Classification of Functioning, Health and Disability
NGO	Non-Government Organisation
PMT	Proxy Means Test
SPF	Social Protection Floor
TQ	Ten Questions Screen
UN	United Nations
UNICEF	United Nations Children's Fund
VFSG	Vulnerable Family Support Grant (in Uganda)
WHO	World Health Organisation
WHODAS 2.0	WHO's Disability Assessment Schedule 2.0

4 Context: Understanding Disability, Poverty and Social Protection

4.1 Understanding Disability

The Australian aid program uses the understanding of disability that is provided by the UN Convention on the Rights of Persons with Disabilities (CRPD):

"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."

Disability is created as a result of the interaction between a health condition, an impairment, functional limitations (which create difficulties for a person in carrying out activities of daily life), and environmental factors. These environmental factors include physical, attitudinal, institutional, communication or other socially created barriers. It is the interaction between these factors that results in a lack of participation, exclusion and discrimination. Disability is not just a health condition in isolation – it is the interaction of this health condition with other factors, which produce exclusion or lack of participation. This multi-dimensional approach is underpinned by the International Classification of Functioning, Disability and Health (ICF).

Previously people with disability were viewed as objects of charity, passive recipients of welfare, or patients in need of "fixing" through medical treatment. A rights-based approach moves towards viewing people with disability as subjects with rights. As subjects under the law, people with disability are capable of claiming their rights and making decisions for their lives based on their free and informed consent and have the right to be active members of society. This approach shows the importance of addressing the institutional and environmental barriers that prevent social and economic participation. It also demonstrates that people with disability are citizens with equal rights to be included in, and benefit from development initiatives such as social protection programs. But often people with disability experience inequality at greater levels compared with people who do not have disability, which means they are unable to negotiate or advocate for their rights on an equal basis with others. Providing access to social protection mechanisms is one way of contributing to the empowerment of people with disability, which can increase their ability to advocate for the removal of barriers and reduce power imbalance and inequity.

People with disability are not a homogenous population. People with disability are men, women, adults, children, poor, rich, ethnically and religiously diverse, dispersed rurally and in urban areas, and exist among populations in all countries. Two people with the same impairment (such as having total vision loss) may have completely different lives depending upon where they live, what access they have to services and how their communities perceive and accommodate them. It is important that aid program staff who are managing social protection programs understand disability, as definitions inform the processes of disability classification (i.e. determining whether or not someone is considered to be a person with disability) and therefore whether and how people with disability are counted and included in social protection programs. National governments have different definition of disability, and some governments may follow the ICF or CRPD understanding, while others may still adopt medical models of impairment. These different approaches to understanding disability and approaching disability classification systems influence the gate-keeping mechanisms of a social protection program (for example, a medical examination to determine disability level or eligibility might be used), and this is a major determinant of whether or not a person with disability participates in a social protection program.

¹ See http://www.who.int/classifications/icf/en/

4.2 Disability and Poverty

The dynamic, cyclical and interlinked impact of disability on poverty at both individual and household levels demonstrates the critical importance of including people with disability in the design, implementation and review of all social protection programs.

The 2011 World Health Organization/World Bank *World Report on Disability* estimates that at least 15 per cent of the world's population (or one billion people) have a disability.² Approximately 80 per cent of people with disability live in developing countries.³

Disability is related to multi-dimensional aspects of poverty

People with disability are more likely to be poor, and they can be among the most vulnerable and marginalised members of any society. Disability is associated with a higher probability of being poor, both in terms of monetary measures and multidimensional measures of poverty including non-economic standard of living aspects like education.⁴ People with disability and their families are more likely to be poor on income or consumption measures and have a lower standard of living because they incur additional costs. These extra costs include direct costs, such as paying for health care services, assistive devices, and costlier transportation options; but there are also indirect costs such as loss of productivity due to being unable to access schooling and employment opportunities.⁵ Evidence shows that children with disability are less likely to attend school.⁶ Frequently people with disability do not have equal access to education and employment,⁷ have large unmet health needs (often unrelated to their disability) compared to the general population, and experience exclusion from everyday life activities.⁸ There is evidence that the disparity between people with disability and the general population increases with overall economic development, with higher disparity in middle-income countries compared to low income countries.⁹ This shows that economic growth does not automatically lead to improved livelihoods for people with disability and their families.

Disability and poverty linkages throughout the lifecycle

Disability risks vary across the lifecycle, and the link between disability and poverty works differently among populations of different ages. Young children face challenges of abandonment, higher mortality rates, potential greater risks of under nutrition, leading through to lower school enrolment. At birth and during early childhood there is also the risk that children with disability will not be supported through early identification, referral and intervention; a lack of intervention at this stage will have impacts for subsequent stages of the life cycle. In old age, there are dramatic increases in the level of disability. ¹⁰ The experience of poverty for older people with disability is often related to the extent to which traditional care and support systems are in place.

² World Health Organisation (WHO) and World Bank (2011). *World Report on Disability*, p.29. Available from: http://www.who.int/disabilities/world_report/2011/en/index.html

³ UN Enable, Factsheet on Persons with Disabilities. Available from: http://www.un.org/disabilities/default.asp?id=18

⁴ Sophie Mitra, Aleksandra Posarac and Brandon Vick (2013). "Disability and Poverty in Developing Countries: A Multidimensional Study". World Development, Vol 41.p.11. Available from: http://dx.doi.org/10.1016/j.worlddev.2012.05.024

⁵ Jeanine Braithwaite and Daniel Mont. 2007. "Disability and poverty: A survey of World Bank Poverty Assessments and implications". Available at: http://siteresources.worldbank.org/DISABILITY/Resources/280658-1239044853210/5995073-1246917324202/braithwaite_and_mont_final_pub_version_ALTER57.pdf. See also Daniel Mont and Nguyen Viet Cuong. 2011.

^{124091/324202/}prattnwate_and_mont_inal_pub_version_ALTERS7.pdf. See also Damer Mont and Nguyen viet Cuong. 20.

[&]quot;Disability and poverty in Vietnam". Available at: http://wber.oxfordjournals.org/content/25/2/323.full.pdf.

⁶ See United Nations Document A/66/230 (2011). "Status of the Convention *on the Rights of the Child*: Report of the Secretary General". Available at: http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N11/442/45/PDF/N1144245.pdf?OpenElement

⁷ See Alexandra Gartrell (2010). "A frog in a well: the exclusion of disabled people from work in Cambodia". Available from: http://www.tandfonline.com/doi/abs/10.1080/09687591003701207

⁸ WHO and World Bank (2011), p.57.

⁹ Mitra, Posarac, and Vick (2013), p.11

¹⁰ WHO and World Bank (2011), pp. 34, 35.

It is also important to recognise that the relationship between disability and poverty can also be dependent upon factors such as the age at which a person acquires an impairment. For example, a child who has had an impairment since birth or early age is less likely to attend school and therefore will have less opportunity to build the human capital to keep them out of poverty later in life. By contrast, people who acquire an impairment later in life may have a lifetime of human capital to draw on and sustain them. This is of course, dependent on their poverty status to begin with. For instance, an unskilled labourer who acquires an impairment may become significantly poorer, whereas the living standard of a highly skilled lawyer who has contributed to and can draw down on a disability pension may experience a change in his/her standard of living if they acquire an impairment, but this may be unlikely to be a catastrophic change.

The heterogeneity of disability, and how this affects the experience of poverty

As disability is conceptualised as the interaction between health conditions, impairments, functional limitations and external factors such as physical or attitudinal barriers, there is a huge diversity of disability. People with disability are heterogeneous, and different people with disability experience disability and poverty differently. The prevalence of disability among women and girls is higher than for men and boys, as women tend to live longer and are at increased risk of acquiring an impairment that can lead to disability due to barriers in accessing health, poor workforce conditions, and due to experiencing violence. Women and girls with disability also generally experience disability differently to men and boys, due to different gender norms. The intersection between gender, disability and poverty can also create new and different forms of discrimination.

Having more than one functioning difficulty is associated with a high risk of being multi-dimensionally poor, compared to people with a single impairment or people without disability. ¹² People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings compared to those who experience physical or sensory impairments. ¹³ There are also impacts with relation to the different needs of (and supports available for) people with varying severity of impairments.

Disability and its relation to household-level poverty

Disability also impacts the vulnerability of a household. Approximately 30 per cent of families live with an immediate family member who has a disability.¹⁴ Disability can often increase household expenditure, due to disability-related expenses such as assistive devices and health care.¹⁵ Households with a person with disability are more likely to experience food insecurity, poor housing, and lack of access to safe water and sanitation.¹⁶ Disability can also increase the income deprivation of a household due to the reduced earning capacity of both the person with disability and their family members. This is because caring responsibilities may reduce education and employment opportunities for other family members. When household income is limited, education of children without (rather than with) disability may be prioritised. Disability can reinforce gender norms and expectations at a household level, with mothers or girls expected to take on the care burden. Boys may have to start work at an earlier age to provide extra household income to cover the additional costs of disability for that household. These factors can have an intergenerational impact on poverty, as children from households with parent/s with disability may be more likely to remain in poverty throughout their lifetime.¹⁷

¹¹ WHO and World Bank (2011), p. 31.

¹² Mitra, Posarac, and Vick (2013), p.11

¹³ WHO and World Bank (2011), p8.

¹⁴ United Nations Statistics Division (1990). Disability Statistics Compendium, Series Y; No. 4.

¹⁵ WHO and World Bank (2011), p. 39.

¹⁶ WHO and World Bank (2011), p. 10.

¹⁷ An indication of this intergenerational impact is seen in recent research from Vietnam that finds that having a parent with disability reduces a child's likelihood of attending school. (Nguyen Viet Cuong and Daniel Mont (2013). "Does Parental Disability Matter to Child Education? Evidence from Vietnam". World Development, Vol. 48. Available from: http://www.sciencedirect.com/science/article/pii/S0305750X13000958

4.3 Definition of Social Protection

This guideline defines social protection as publicly funded initiatives that provide regular and predictable cash or in-kind transfers to individuals, households and communities to reduce poverty and vulnerability and foster resilience and empowerment.

4.4 Disability and Social Protection Programs

Key international frameworks

There are several international frameworks that provide guidance on social protection and people with disability. Article 28 (Adequate Standard of Living and Social Protection) of the CRPD notes that people with disability have a right to social protection and should not be discriminated against on the basis of disability. It requires States Party to ensure access by people with disability to social protection programs, including assistance with disability-related expenses. The International Labour Organisation Convention 102 (1952) on Social Security (Minimum Standards) includes specific reference to an 'invalidity benefit' (Part IX) which is relevant to people with disability. While work is ongoing, people with disability are considered part of the constituency for development of the Social Protection Floor (SPF).¹⁸

Disability in social protection programs – two approaches

In general, there can be two types of social protection programs relevant to people with disability: (1) those programs that specifically target and include only people with disability, known herein as "disability-specific social protection programs", and (2) those programs where people with disability may be included as part of a larger beneficiary population, herein referred to as "mainstream social protection programs".

Disability-specific social protection programs

Disability-specific social protection programs can provide a critical safety net for people with disability who have high support needs and may be unable to participate in or benefit from other mainstream social protection programs. They can also provide goods and services which address the specific needs of people with disability. Disability-specific cash transfers can potentially improve the status of people with disability within the household as they are seen as contributing members. It is important to remember that not all people with disability will require disability-specific social protection programs. For some, access to mainstream social protection programs may be sufficient to address their needs.

¹⁸ The Social Protection Floor (SPF) approach was developed by the ILO as an integrated set of social policies designed to guarantee income security and access to essential social services for all. See http://www.socialprotectionfloor-gateway.org/

An example of disability-specific social protection

Brazil's Continuous Cash Benefit Program (known as BPC, which stands for Beneficio de Prestacao Continuada) is an unconditional cash transfer to extremely poor people with disability and the elderly. A paper on the scheme written in 2006¹ noted that BPC is the second largest noncontributory cash benefits program in Brazil, second only to Bolsa Familia. To be eligible to receive BPC, a person with disability must have household per capita income that is less than one-quarter of the minimum wage. They must also be classified as having a "severe" disability that hinders their independent life and ability to work. This is assessed by medical experts (see discussion of how to classify disability and determine eligibility in section 4.1 below).

Examples of disability-specific social protection programs include: cash transfers provided only to people with disability based on specific disability classification and/or poverty criteria; cash or in-kind benefits which fund, on a regular and predictable basis, specific needs of people with disability, which includes assistive devices such as mobility or communication aids or rehabilitation services.

Mainstream social protection programs

Examples of mainstream social protection programs, from which people with disability may benefit, include: cash transfers, including targeted (e.g. at the poorest quintile), categorical (e.g. all school-aged children or all older persons) and universal (e.g. health care for all); social insurance schemes which provide benefits or payments for contributors who become temporarily ill or acquire an impairment and are unable to work; ¹⁹ public work programs or cash-for-work programs; in-kind benefits such as food-for-work; fee waivers for essential services such as health and education, or scholarships; general price subsidies, for example for food or fuel.

A combination approach: a social protection system that combines both specific and mainstream support for people with disability

Ideally, many people with disability would benefit from both disability-specific and mainstream social protection programs. For example, they would receive disability-specific social protection by way of in-kind benefits which covers the additional cost of disability they may face (such as a program that provides free assistive devices like a prosthetic limb, crutches or wheelchair, as well as free transport to and from the service centre, and accommodation if required), and they would also participate in broader education, vocational training and cash-for-work social protection programs (and their participation in these programs is facilitated by adaptations to these programs to make them accessible).

An example of taking a "life cycle" approach that combines disability-specific and mainstream social protection support

South Africa offers people with disability access to a range of social protection schemes across the lifecycle. These schemes are a combination of disability-specific schemes that are only targeted to people or households with disability, as well as mainstream programs from which people with disability can benefit. In the South African system, families with a child with a disability under 18 years receive a 'Care Dependency Grant'. People with disability who are aged 18-60 years are provided with a 'Disability Benefit'. And all people over a certain age threshold receive an 'Old Age Pension'.

¹⁹ While social insurance schemes can help to protect people who acquire a disability from becoming poor, they do not address the needs of the 15 per cent of the world's population who already have a disability. In addition, such schemes are structured around formal workforce participation. But in many developing countries most people work in the informal workforce, hence access to social insurance schemes may be limited. Where people with disability are included in the formal workforce and where contributory schemes are in place, it is important to make sure this includes the specific needs of employees with disability.

Social Protection is only part of the solution for people with disability

It is widely recognised that social protection programs should not be seen as the single panacea for solving poverty; rather they should be seen as complementary to other service delivery supply initiatives. The same is true for reducing poverty for people with disability – while inclusion in disability-specific and/or mainstream social protection programs can make a significant contribution, it will be insufficient in itself to eliminate poverty for people with disability and to ensure they enjoy the same access to opportunities and standard of living as other citizens. For example, even if a family received cash transfers to send children to school, it doesn't necessarily mean the school is accessible for children with disability. It won't, for instance, address barriers relating to the attitude of families (do they want to send their child to school?), skills and attitude of the teacher, or accessibility of the classroom and learning materials.

5 The Social Protection Program Cycle: Key Issues to consider for disability-inclusion

5.1 Design

Consultation with people with disability and their representative organisations during design is invaluable to gain an insight into potential barriers people with disability may face in participating in development activities and strategies to overcome them. It also helps to build their capacity to engage with governments and development organisations in the future.

As outlined above, people with disability would ideally be able to benefit from both disability-specific and mainstream social protection programs. Unfortunately, this ideal situation does not exist in many countries, particularly in developing countries. Many of our partner countries might feel the need to make difficult decisions on what types of social protection program they can implement within existing resources. It is important that governments are making these kinds of decisions based on what sort of program(s) will most benefit people with disability, both now and into the future.

In order to support informed decisions, when we are involved in the design phase for any social protection program, we should encourage dedicated analysis of the need and capacity for the development of opportunities and barriers for people with disability to participate in and benefit from both disability-specific and mainstream social protection programs. The analysis should cover current programs, as well as analysing gaps and making recommendations for new programs.

Methodology and approach to the analysis

The analysis to inform program design should involve rigorous assessment of alternatives and tradeoffs between and within different types of disability-specific and mainstream social programs. It should also challenge existing assumptions among policy makers about people with disability, for example that they cannot participate in or benefit from public works programs. The analysis should cover current programs, as well as analysing gaps and making recommendations for new programs.

Additionally, there is a need to consider whether broader complementary policies and programs could be introduced to provide equality of opportunities, challenge community attitudes, and reduce stigma of disability, in order to facilitate people with disability achieving security of livelihood. For example, in addition to the provision of pensions, we should also increase over time employment opportunities for people with disability, enabling them to secure work rather than rely on pensions.

Government institutions with specific responsibility for disability policies and programs (such as ministries of social affairs or disability councils) should be included in the needs analysis for social protection programs for people with disability. In general, these institutions have responsibility for working with other line Ministries/government institutions to provide advice on issues that relate to people with disability and/or directly managing some services (such as physical rehabilitation). Early involvement of these institutions will assist in making informed decisions on whether and how they might play a role in implementing social protection programs relevant to people with disability.

People with disability are experts in their own lives and are best placed to provide advice on the barriers they face in daily life (thus ensuring programs are informed by the 'lived experience' of people with disability). Good quality analysis therefore requires direct involvement by people with disability, which can be facilitated through the involvement of disabled people's organisations. It is important here to recognise that disabled people's organisations may not fully represent the diversity of disability. In particular, women with disability and people with intellectual impairments are often inadequately represented by disabled people's organisations, meaning we may need to put extra effort into consulting these groups. We should always seek self-representation of people with disability, but in some

situations, families and carers may be the only way to represent the views of people with intellectual and psychosocial impairments where they are not able to effectively advocate for themselves.²⁰

Including DPOs as partners in the analysis can also help to determine whether and how they might have an ongoing role in implementation. This could, for example, include:

- DPOs providing advice on strategies to increase the accessibility of social protection programs, such as how to ensure that community awareness reaches people with disability, that targeting mechanisms are sensitive to disability, and that grievance and appeals processes are accessible to people who are blind or deaf or who may have an intellectual disability, for example.
- DPOs being a conduit for information on social protection program opportunities to their members at a village level. DPOs can often reach people with disability who may not be reached by other organisations, including even local village chiefs or local NGOs.
- DPOs providing disability awareness training to people involved in disability classification and targeting mechanisms (either community-based or by local government), or by enabling DPO members to have a role in this type of activity.

Consulting with families and carers of people with disability is also essential to enable us to understand the impact disability can have on poverty more broadly (including through reduced social and economic opportunity for other household members).

Supporting collaboration between national social protection institutions, DPOs or self-help groups of people with disability, and government institutions with responsibility for disability through the process of analysis can itself be mutually beneficial. For example, DPOs can learn more about social protection programs in order to inform their own advocacy efforts or to provide information to their members, while social protection institutions can learn about the barriers directly from the people who experience them (which can be a very effective awareness-raising and capacity development method).

An example of analysis to inform the design of inclusive social protection programs

In response to interest from the Government of Indonesia, the Australian Government has supported analysis of options for disability benefits. The analysis examines the interaction of poverty and disability in Indonesia across the lifecycle, and highlights the important role social protection should play in supporting people with disability. It recommends an approach for developing a comprehensive social protection system that includes people with disability in Indonesia.

Key issues to address in the analysis

Analysis during the program design phase of barriers and opportunities for people with disability to participate in and benefit from both disability-specific and mainstream social protection programs requires careful consideration of several challenging issues. Disability classification and targeting are particularly complex. These issues are covered in detail below.

Identifying, classifying and targeting people with disability in social protection

In recognition that people with disability are among the most marginalised and poorest, social protection programs may want to target people with disability to be beneficiaries of a program, or make being a person with disability one of the criteria for eligibility. Determining how to assess disability and classify who is a person with disability for program eligibility purposes is therefore an important step. Some issues to consider when targeting people with disability are outlined here.

²⁰ In this situation, it is important to be aware of dynamics between people with disability and families/carers. Research has found that people with disability face a higher rate of violence or abuse than people without disability, including violence perpetrated by family members. Often people with communication or cognition impairments can have less access to protective services because their point of contact with social services is their abuser. Family/carers may also have other interests that may not reflect the interests of the person with disability. For example, a person with disability may be pressured to not become employed because their family wants to ensure their unemployment or disability pension continues.

Current approaches to disability classification in disability-specific social protection programs

When a social protection program is targeted at people with disability, and being a person with a disability is an eligibility requirement, systems to identify people with disability are required. Disability classification within such programs is often based on national definitions of disability (which can be found in national legislation – either through a specific law on disability and/or across multiple other laws such as on employment or access to health). Disability can also be defined in government policies, such as a national disability policy. But in many countries, these national definitions are not aligned with international best-practice based on the CRPD and ICF. Instead, determining who is a person with disability, for the purposes for example of a disability-specific social protection program, can often rely too heavily on a medical approach, focusing on diagnosis of health conditions which led to impairment. This approach ignores the inter-relationship of an impairment with other external factors such as institutional and environmental barriers. A further challenge with an over-reliance on a medical approach is that many developing countries do not have sufficient numbers of qualified and experienced health and allied professionals to undertake good quality multi-disciplinary assessment of health conditions. The flow-on effect from this could be the potential exclusion of large numbers of people with disability, in particular those groups of people who may have impairments that cannot be seen (such as intellectual or psychosocial).

Current approaches to disability classification in mainstream social protection programs

Determining eligibility for mainstream social protection programs is often determined by a poverty assessment such as a Proxy Means Test (PMT). It is often assumed that people with disability will be automatically captured by such targeting mechanisms, given that people with disability are overrepresented among the poor. However, there are challenges in this approach. By collecting information at a household level, people with disability are invisible, and we will therefore not know whether people with disability are benefitting or not. Furthermore, households which include people with disability have been found to face higher costs, and to have a lower standard of living at the same income level. To determine which households include people with disability, simply asking a single question along the lines of "do you, or anyone else in the household have a disability?" has been shown to be unreliable for several reasons, such as:

- the significant stigma and discrimination surrounding disability means some people may feel ashamed to identify as having a disability and therefore not self-disclose
- the words "disability" and "impairment" often do not translate easily into local languages, or locally used words have negative or offensive connotations
- a person may not consider themselves to have a disability, if for example, they consider their impairment a normal part of aging, haven't had a health condition formally diagnosed, or think only severe impairment counts
- enumerators can influence responses by asking questions in ways that are insensitive and/or culturally inappropriate.

Practitioners are also beginning to examine whether PMT or other poverty assessments need to include some form of weighting for disability classification to enable such poverty targeting measures to be sensitive to the extra costs of disability households with members with disability face. Community-based targeting is another common mechanism that may be used in conjunction with other approaches to inform mainstream social protection programs. When village leaders are responsible for identifying people with disability in their villages they may not know all the people with disability in their community because the disability might be invisible or undisclosed, or stigma and discrimination might mean people with disability are well-hidden by their family.

Possible alternatives to disability classification

²¹ For a discussion on the extra costs of disability, see Jeanine Braithwaite and Daniel Mont (2009). "Disability and Poverty: A survey of World Bank Poverty Assessments and implications". Available from http://siteresources.worldbank.org/DISABILITY/Resources/280658-1239044853210/5995073-1246917324202/braithwaite_and_mont_final_pub_version_ALTER57.pdf.

To improve disability identification and classification in both disability-specific and mainstream social protection programs, there are two alternative approaches which could be used to identify the population who are at risk of disability.

The first approach is to use the WHO's Disability Assessment Schedule 2.0 (WHODAS 2.0).²² The WHODAS 2.0 is a practical instrument to measure general health and disability levels (refer Annex 1). It captures the level of functioning in six domains of life (cognition, mobility, self-care, getting along, life activities and participation). The instrument allows determination of both domain-specific functioning and an overall summary score of functioning and disability that is reliable and applicable across cultures in all adult populations. A potential benefit of this approach is that it provides relatively comprehensive information and a summary score about the difficulties a person with disability may face in their daily life, thereby providing more detailed information to assist with decision-making on which people with disability to target, and can even help design the most appropriate approach to the program (for example, whether it should be cash or in-kind transfers) and what type of specialised or support services the person may require (such as assistive devices). By giving functioning domain-specific information, the WHODAS 2.0 can also help set thresholds of targeting. For example, a social protection program may not want to target all people with disability, but only those with "severe" functioning difficulties.

Another approach is to incorporate the approach to data collection developed by the Washington Group on Disability Statistics into beneficiary targeting and identification processes. The Washington Group has developed an approach to disability data that has proven to be the most effective way of getting reliable disability prevalence information through a census. This is known as the 'Short Set of Six Questions' (refer Annex 2). This approach works because it is based on the ICF (so focuses on functioning, not just impairments) and does not actually use the word "disability" (so reduces the risk of people not identifying as having a disability due to stigma and discrimination). Including these questions in mechanisms such as PMTs will allow us to know who is at risk of disability and who might require support through social protection programs.

Use of either the WHODAS 2.0 or the Washington Group questions would be appropriate in both disability specific and mainstream social protection program for the purpose of identifying the population who are at risk of disability. Deciding which method to use might therefore be based on the space and time available, with the WHODAS 2.0 being more extensive and involving more questions than the shortest version of the Washington Group approach which was limited to a minimum of six questions. It is also important to note that neither of these tools was designed specifically for social protection eligibility purposes, so once the population at risk of disability was identified, additional eligibility criteria (such as poverty levels) or independent disability and "needs" assessment would be needed to ensure the right people are getting the right support.

Challenging issues in disability classification, eligibility and targeting

Self-identification. Methods to classify someone as a person with disability (the WHODAS 2.0) and to identify people with disability through surveys (the Washington Group Short Set of Six Questions) all rely on self-identification, with the person with disability (or possibly a head of household) providing answers to questions. This approach may lead to challenges relating to fraud. Some people could knowingly provide incorrect responses to questions in order to be included in the program (this is known as "inclusion error"). Adding diagnosis of health condition to the disability classification process could potentially reduce inclusion error, but only in those countries where there are sufficient and accessible health and allied professionals.²⁴ But introducing an approach to classification based on medical diagnosis prematurely could increase barriers for people with disability being included in and benefiting from the programs (known as "exclusion error"). It is also important to remember that the significant

²² Refer: http://www.who.int/classifications/icf/whodasii/en/.

²³ Refer: http://www.cdc.gov/nchs/washington_group.htm.

²⁴ Note: this will also not be perfect, even developed countries with sophisticated and multi-disciplinary assessment processes still have inclusion errors.

stigma and discrimination people with disability face in many developing countries could serve as a deterrent for people falsely identifying as having a disability. Legislation on social protection should make it illegal for people to knowingly submit false responses to questions and include mechanisms for punishment that can serve as a disincentive. However, given the complex nature of disability, the issue of falsifying information needs to be managed carefully. Development of systems to reduce inclusion error should be balanced against increasing administrative costs, and exclusion errors (i.e. more people with disability missing out).²⁵

Cut-Off Point. While the WHODAS 2.0 and the Washington Group Short Set of Six Questions provide information about the functional limitations of an individual, a decision needs to be made on what degree of functional limitation should be the "cut-off point" for being eligible for the social protection program. This will be informed by the purpose of the program (is it providing services only for those people with severe disability/high support needs?) and the fiscal envelope.

Children with disability. There are additional challenges in disability classification for children. They may not be able to answer questions directly themselves, either because they are too young to communicate effectively or because of the nature of their impairment. In these situations it often falls to parents or caregivers to respond on behalf of children. This may be difficult, as they may not be aware of normal developmental milestones for children in order to determine whether or not the child is progressing as should be expected. The WHODAS 2.0 and the Washington Group Short Set of Six Questions are not designed to capture data on children with disability. An adaptation of the Washington Group approach which focuses specifically on identifying children with disability is the Ten Questions Screen approach (TQ, refer Annex 3). There are however, some issues with this particular tool which the Washington Group and UNICEF are currently working to address through the development of an improved module (likely to be ready by 2015).

Intellectual and psychosocial impairments. The WHODAS 2.0, the Washington Group Short Set of Six Questions and the TQ approach are all known to have challenges in sufficiently identifying children and adults with intellectual and psychosocial disability. This doesn't mean these tools shouldn't be used, but just that some adaptations (informed by appropriate expertise) and pilot testing may be required.

Gaps in assessment periods. Eligibility for poverty-targeted social protection programs, such as those using PMTs, is often determined on a periodic basis. For people who miss out (or acquire a disability during this period), the delay before the next assessment round can result in significant hardship. Ensuring programs are responsive to disability and enable enrolment at any time is important.

Appeals processes and grievance mechanisms. Many social protection programs have an appeals or grievance processes whereby people can dispute exclusion and inclusion. The effectiveness of these mechanisms is often low, but it is important to note that these processes can be particularly inaccessible to people with disability. They might not be aware it exists, be unable to access an appeals office (due to distance, cost of transport etc.), and be unable to complete a form, or not be able to communicate (for example if sign language interpretation is not available). DPOs could be a helpful intermediary in these processes. DPOs can also help up-front to make sure people with disability know about the program, people with disability's right to access it, and how to apply.

The costs. Being included in social protection programs can come at a higher cost for people with disability and their families which may itself be a barrier and disincentive. For example, the cost of getting to a centre to go through a disability classification process could be prohibitive (some people

 $^{^{25}\} UK\ Department\ for\ International\ Development\ (2011).\ Cash\ Transfers\ Evidence\ Paper,\ p.53$

²⁶ It is important to note that the WHODAS 2.0, the Washington Group and the TQ approach have not previously been used to determine disability classification for mainstream social protection programs. The use of these methodologies should be approached with care, including through the involvement of appropriate expertise and sufficient piloting, validity and sensitivity testing in-country.

with disability may need to travel with a carer or are unable to use common, and cheap transport like motorbikes).

Issues of disability classification, targeting and eligibility to consider during analysis and design

In order to support informed decisions about how to classify and identify disability, analysis and decision-making during program design should:

- a) Source the official national definition of disability. Assess whether and how it is harmonised across all relevant legislation/policy and aligned to the CRPD/ICF.
- b) Study current approaches to disability classification, including whether and how they are consistent with the WHODAS 2.0, the Washington Group Short Set of Six Questions and the Ten Questions approach, and whether adaptations are required.
- c) Consider risks and mitigating strategies relating to self-identification and how these can be balanced against potentially increasing administrative costs and exclusion error.
- d) Assess the overall fiscal envelope available for disability-specific and mainstream social protection programs that include people with disability. This may require some political economy analysis to understand the drivers for resource allocation.
- e) Assess cut-off points for eligibility which are relevant to the purpose of the program and fiscal envelope.
- f) Assess targeting decisions and mechanisms for mainstream programs, including whether and how disability classification has informed poverty status.
- g) Determine whether people with disability have been included in population-based poverty analysis, and the reliability of this information.
- h) Examine how gaps in targeting periods can be managed.
- i) Examine the benefits and challenges with alternative targeting mechanisms, including community-based targeting. (This aspect in particular will need to take account of attitudes towards people with disability).

Benefit types and levels

The purpose of the social protection program in question will guide decisions about benefit type such as whether to provide cash transfers or in-kind transfers. If the purpose is to provide income assistance if a person is unable to work, then cash transfer is likely to be the most appropriate benefit type. But issues such as household power dynamics should also be taken into account when designing the program and deciding on the appropriate benefit type. How cash is transferred and whether or not people with disability can access the transmission mechanism (bank, government office in provincial capital town etc.) and whether or not a proxy (family member, carers etc.) can receive the transfer need to be considered. In some programs, it may be decided that cash payment agents visit people with disability in their homes if they are unable to access the centre or office that is operating as the cash distribution point.

There exists no best practice formula to guide benefit levels, such as the appropriate amount of a cash transfer. Typically, transfers are set below the minimum wage so as not to encourage employment disincentive effects. However, the literature suggests that such amounts are not sufficient to cover the additional costs associated with living with a disability. There is also suggestion that employment disincentive effects may be less warranted in developing country contexts. It has been argued that cash transfers targeted for people with disability should be designed so as to cover both the costs associated

²⁷ For example, some evidence from South Africa suggests old age and disability pensions are controlled by relatives. See for example Sophie Mitra (2005). "Disability and Social Safety Nets in Development Countries". World Bank Social Protection Discussion Paper Series. Available from: http://sitesources.worldbank.org/SOCIALPROTECTION/Resources/0509.pdf.

with living with a disability as well as the loss of income experienced by a person or household with disability.

In-kind provisions can be used to support the provision of assistive devices that facilitate the participation of people with disability in economic activity or improve access to services. For example, a social protection program could support a person with disability to attend a centre for assistive device provision (this could be facilitated through a voucher system or free transport for example)²⁸ or could enable health care workers to undertake outreach visits to provide physical therapy. In-kind transfers such as this require systems to ensure service provider costs are covered. Without this, there are risks that the quality and quantity of services will be poor due to lack of funding. Care also needs to be taken to ensure that subsidies do not simply drive up the cost of the supplies or services. Services provided on an in-kind basis also need to ensure they meet the diverse needs of people with disability, noting that some groups (such as those with intellectual and psychosocial disability) are often under-served. In-kind transfers can also guarantee that the benefit accrues directly to the person with disability, as opposed to the household.

Issues of benefit level and type to consider during analysis and design

In order to support informed decisions about how to classify and identify disability, analysis and decision-making during program design should:

- a) Examine disability-specific cash or in-kind transfers, including relevant issues such as control of cash transfers within the household and use of proxy recipients and whether universal or targeted approaches are appropriate.
- b) Understand whether the supply of services, both mainstream (such as basic education) and those specific to people with disability (rehabilitation and disability services) are available, acceptable to and accessible for people with disability (including people with a range of different impairments, such as vision, hearing, mobility, intellectual and psychosocial).

5.2 Implementation and Review

Social protection programs dedicated to or inclusive of people with disability are still relatively new in developing countries and there is limited solid international evidence on what works, what doesn't and why. Reviews and evaluations are an important opportunity to further build the evidence base about the importance of social protection programs that include and/or target people with disability.

A good quality design process informed by dedicated analysis will enhance the likelihood of successful implementation of social protection programs relevant to people with disability. However, unforeseen challenges, as well as opportunities, will inevitably arise during implementation that will need to be considered and addressed.

Monitoring and gathering evidence

Social protection programs dedicated to or inclusive of people with disability are still relatively new in developing countries and there is limited solid international evidence base on what works, what does not and why.²⁹ Owing to the stigma, discrimination and other barriers people with disability face, they can be invisible in communities and less likely to complain. For these reasons, regular formal, informal, qualitative and quantitative processes to monitor and review the participation of people with disability in social protection programs should be incorporated in the design and included in implementation. This will improve the quality of the program through early identification of issues and enabling informed decisions about possible adaptations to design. There are several principles and approaches

²⁸ Common assistive devices include spectacles, prostheses and orthoses, blind canes, hearing aids, walking sticks, crutches, wheelchairs, and devices to help with daily activities.

 $^{^{29}}$ This gap and the need to address it through multiple means is identified in WHO and World Bank (2011), p. 47.

that should be incorporated to ensure a participatory and learning approach to implementation and review, which are outlined here.

Providing an opportunity for DPOs to represent people with disability in regular governance and coordination mechanisms for social protection at all levels (national and sub-national) will help to ensure feedback is provided directly to decision-makers and potential issues identified and addressed early.³⁰ They can also support formal monitoring and reviews at the community level as they are more likely (compared to other non-government organisations, or local government officials) to find and facilitate the inclusion of people with disability. Bringing the 'lived experience' of people with disability to program implementation and review is just as important as including it in the design.

Government institutions with responsibility for disability should also be included. They can sometimes be best-placed to provide advice where multi-sectoral issues arise, in particular around the supply of disability-inclusive services (such as primary health care or basic education).

Formal review processes need to be explicit in terms of reference in asking 'whether and how people with disability were included in and benefited from the program'. Even if the design didn't explicitly include people with disability, asking the question during a review can help identify gaps and opportunities to reduce exclusion in future. People with disability are sometimes considered an implicit part of "vulnerable groups" for social protection programs. But this approach is not considered effective because it does not distinguish the different barriers people with disability face compared to other vulnerable groups, and the diverse approaches required to ensure their inclusion.

An example of analysis to gather evidence about whether people with disability have been able to benefit from social protection programs

The Philippines Country Program commissioned a study to examine whether people with disability have been able to benefit from the Government of Philippines' conditional cash transfer program, Pantawid Pamilyang Pilipino Program, implemented by the Department of Social Welfare and Development (DSWD). The analysis found that many people with disability were inadvertently excluded from this program because of the conditionality requirements relating to attending school. Children with disability who were deemed to experience challenges in complying with the requirements were not prioritised to receive the cash transfer. The study found that this practice has discriminatory effects, given that it is often external factors such as environmental, structural, attitudinal and administrative barriers that prevent people with disability fulfilling conditions. The Australian Government and DSWD are now using this research as a reference in introducing enhancements to the program and in engaging other Philippine government agencies to make the program more inclusive and accessible for people with disability.

³⁰ It is important here to recognise that DPOs may not fully represent the diversity of disability and women with disability and people with intellectual impairments are often inadequately represented by DPOs. We need to consider this when we are using DPOs as a channel to consult with people with disability.

6 Summary: What you can do

Opportunities to implement the suggested approaches outlined in the following section will vary depending on a range of considerations including the country context, the institutional capacity of implementing partners, and the operational environment involved. For example, when the Australian Government becomes involved in a social protection program, often implementing partners or the partner government have already chosen targeting mechanisms, at which point we are unlikely to be in a position to influence the methodology used to target people with disability. We therefore need to assess entry points based on where we can best influence and promote disability inclusion.

6.1 Design

- 1. Begin to **increase your own awareness** about the situation for people with disability and their families in the proposed program location. Consider barriers that may be faced by people with disability in participating or benefiting from a proposed program, giving particular consideration to the different needs of women, men, girls and boys with disability. If a delivery strategy or country situation analysis has been completed and this includes information about people with disability, this is a good starting point.
- 2. If you are determining a budget for a program design phase, **include budget provision** for consultation with DPOs and people with disability (remembering to cover potential costs related to such consultations, such as transport, sign language interpreters etc.) and analysis.
- 3. Consider what additional **analysis** (if any) will be needed in the design phase, and commission dedicated analysis on the barriers and opportunities for people with disability and their families to be included in and benefit from both disability-specific and mainstream social protection programs.
- 4. **Consult with DPOs** to help you identify relevant issues. It is important to ensure the direct and meaningful involvement in this analysis of people with disability, through DPOs, and government institutions with responsibility for disability.
- 5. Ensure the design of social protection programs considers **issues of disability classification**, **targeting and eligibility** as well as benefit level and type.
- 6. Work with implementing partners (both government and NGOs) to **make informed design decisions** on adaptations and/or new initiatives for either/both disability-specific and mainstream social protection programs.

6.2 Implementation and Review

- 7. Support the inclusion of DPOs and government institutions with responsibility for disability in regular **governance and coordination mechanisms** for social protection programs at all levels (national and sub-national). Ensure they have sufficient capacity to engage in a meaningful way in these mechanisms.
- 8. **Ensure disability is made explicit in reviews** of social protection programs. This will contribute to building a strong evidence base on disability and poverty. Include an explicit question in the Terms of Reference for reviews, along the lines of "Were people with disability included in and able to benefit from this program? How? To what extent?"
- 9. **Facilitate the involvement of DPOs** in regular formal, informal, qualitative and quantitative monitoring and evaluative processes for all social protection programs.
- 10. Pay particular attention to **disability classification and targeting** during implementation and review.

Annex 1 World Health Organization Disability Assessment Schedule 2.0

Self-Administered 12-Item Version – The Self-Administered 12-Item Version was developed to assess and classify disability. This particular instrument version of the WHODAS 2.0 is the self-administered 12-item version. There is also an interviewer-administered 12-item questionnaire, as well as other versions (36-item version, 12+24 item).

This questionnaire asks about <u>difficulties due to health conditions</u>. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs. Think back over the <u>past 30 days</u> and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, <u>please circle only one</u> response.

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S1	Standing for long periods such as 30 minutes?	1	2	3	4	5
S2	Taking care of your <u>household responsibilities</u> ?	1	2	3	4	5
S3	Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
S4	How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5
S5	How much have <u>you</u> been <u>emotionally</u> <u>affected</u> by your health problems?	1	2	3	4	5

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
S6	Concentrating on doing something for ten minutes?	1	2	3	4	5
S7	Walking a long distance such as a kilometre [or equivalent]?	1	2	3	4	5
S8	Washing your whole body?	1	2	3	4	5
S9	Getting dressed?	1	2	3	4	5
S10	<u>Dealing</u> with people <u>you do not know</u> ?	1	2	3	4	5
S11	Maintaining a friendship?	1	2	3	4	5
S12	Your day-to-day work/school?	1	2	3	4	5

H1	Overall, in the past 30 days, <u>how many days</u> were these difficulties present?	Record number of days
H2	In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?	Record number of days
НЗ	In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition?	Record number of days

Annex 2

Washington Group Short Set of Six Questions

The following set of questions was prepared for insertion into national census instruments. It is important to consider if this is appropriate to the context and type of social protection program being implemented and or reviewed.

The following questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM:

- 1) Do you have difficulty seeing, even if wearing glasses?
 - a) No no difficulty
 - b) Yes some difficulty
 - c) Yes a lot of difficulty
 - d) Yes cannot do at all
- 2) Do you have difficulty hearing, even if using a hearing aid?
 - a) No no difficulty
 - b) Yes some difficulty
 - c) Yes a lot of difficulty
 - d) Yes cannot do at all
- 3) Do you have difficulty walking or climbing steps?
 - a) No no difficulty
 - b) Yes some difficulty
 - c) Yes a lot of difficulty
 - d) Yes cannot do at all
- 4) Do you have difficulty remembering or concentrating?
 - a) No no difficulty
 - b) Yes some difficulty
 - c) Yes a lot of difficulty
 - d) Yes cannot do at all
- 5) Do you have difficulty (with self-care such as) washing all over or dressing?
 - a) No no difficulty
 - b) Yes some difficulty
 - c) Yes a lot of difficulty
 - d) Yes cannot do at all
- 6) Using your language, do you have difficulty communicating, for example understanding or being understood?
 - a) No no difficulty
 - b) Yes some difficulty
 - c) Yes a lot of difficulty
 - d) Yes cannot do at all

Annex 3

The Ten Question Screen

The following set of questions was prepared to screen for "severe" disability among children aged 2-9 years. These questions are part of a broader screening approach which includes follow-up medical assessment. The Ten Question Screen process has been included in UNICEF's Multiple Indicator Cluster Surveys in a number of countries. It is important to consider if this is appropriate to the context and type of social protection program being implemented and/or reviewed.

- 1) Compared with other children, does or did (*name*) have any serious delay in sitting, standing, or walking?
- 2) Compared with other children does (*name*) have difficulty seeing, either in the daytime or at night?
- 3) Does (*name*) appear to have difficulty hearing? (uses hearing aid, hears with difficulty, completely deaf?)
- 4) When you tell (name) to do something, does he/she seem to understand what you are saying?
- 5) Does (*name*) have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?
- 6) Does (name) sometimes have fits, become rigid, or lose consciousness?
- 7) Does (name) learn to do things like other children his/her age?
- 8) Does (*name*) speak at all (can he/she make himself or herself understood in words; can he/she say any recognizable words)?
- 9) a. (For 3-9 year olds): Is (*name*)'s speech in any way different from normal? (not clear enough to be understood by people other than the immediate family?
 - b. (For 2 year olds): Can (*name*) name at least one object (for example, an animal, a toy, a cup, a spoon)?
- 10) Compared with other children of his/her age, does (*name*) appear in any way mentally backward, dull or slow?

A child is screened positively for disability if the answer is "Yes" to one or more of the questions, and this screening is validated by the medical assessment.