



INCLUSIVE SOCIAL PROTECTION FOR EMPOWERMENT OF PERSONS WITH DISABILITIES

BACKGROUND PAPER # 2

Considering the Disability related Extra Costs in Social Protection

Advanced unedited draft for consultation

June 2020

A collaboration between



ACKNOWLEDGEMENTS

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This background paper is a part of a series produced in the frame of a project led by ILO and UNICEF in close collaboration with the International Disability Alliance (IDA) and supported by the UN Partnership on the Rights of Persons with Disabilities. It has been co-financed by Leonard Cheshire in the frame of the DFID funded I2I project.

The UNPRPD project aims at developing practical guidance for countries, development agencies and DPOs for reforms towards inclusive social protection systems fostering empowerment of persons with disabilities across the life cycle.

The papers summarize key issues and present policy recommendations and proposal to build inclusive social protection systems supporting empowerment and participation of persons with disabilities across the life cycle. Advanced unedited versions of the papers are disseminated for consultation with experts and activists from social protection and disability rights communities.

Any comments and suggestions on issues highlighted, recommendations and proposals should be sent to Quynh Anh Nguyen at nguyeng@ilo.org

Feedback received contributes to the finalization of the papers and the elaboration of a comprehensive guidance document.

List of background papers

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2. Considering Disability Related Extra Costs in Social Protection
3. Social Protection and Employment of Persons with Disabilities
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INTRODUCTION

The goal of the UN Convention on the Rights of Persons with Disabilities (CRPD) is to ensure that all persons with disabilities exercise and enjoy all human rights on an equal basis with others. This does not imply only access to similar resources as those without disabilities. Indeed, due to barriers in infrastructure, transports, services and the workplace as well as lack of support, persons with disabilities and their families have to spend more than those without disabilities to access essential services or achieve social and economic participation.

In addition to having to spend more to achieve the same standards of living, they also tend to earn less income due to barriers in employment and opportunity costs incurred by family members providing support. Together, those additional expenses and forgone income constitute the disability related costs which prevent them to seize economic opportunities and achieve a similar standard of living and participation. This creates a vicious circle that social protection can help break with a well-designed combination of schemes.

The paper will tackle several critical elements required for social protection systems and programs to adequately consider disability related extra costs. In the first part, it will explain the diversity of disability related costs. The second part will present current methods to assess and measure disability related costs and the issues they raise. The last part will present how social protection systems can take into account and tackle those different disability related costs. The details of design of cash transfers or in-kind support will be addressed in other papers in this series.

The diversity of disability related extra costs

Disability related costs are diverse, and their type and extent depend on:

- A person's functional difficulties, health conditions and support needs
- The level of accessibility and inclusiveness of their environment
- A person's level of participation.

For social protection systems to effectively support persons with disabilities, they must account for this diversity, measure those costs and provide adequate responses.

Persons with disabilities and their families face:

- *Direct costs.* These are the extra expenditures required due to having a disability. They include increased spending on regular goods and services as well as the purchase of disability specific devices and services.
- *Indirect costs.* This includes lower levels of earnings for people with disabilities because of limited access to education and barriers to gain and retain employment, as well as the opportunity costs of foregone income for family members giving up school and/or work opportunities to provide support.

Table 1 Example of disability related extra costs

EXAMPLE OF DISABILITY RELATED EXTRA COSTS		
DIRECT COSTS		INDIRECT COSTS
Extra spending on regular items	Disability specific related spending	
Higher needs in health care	Assistive devices	Lower education
Higher transportation costs due to inaccessibility	(Re)Habilitation services	Lower employability and earnings
Higher need for childcare (more intensive and for a longer period of time)	Human assistance such as interpreters or personal assistance	OPPORTUNITY COSTS Loss of income for primary family care and support provider
Exclusion from community or need to be close to services may oblige families to relocate in more expensive areas	Transportation to reach specific services that are not available in the community	Lower capacity to invest in productive assets of children education

Some direct costs are from the **higher consumption of ordinary goods and services** that all people use but are of higher necessity for people with disabilities. Health care and transportation are prime examples. As one man from Philippines who uses a wheelchair and is an IT professional explained:

“My boss was ready to adapt my workplace, but the buses were not accessible, and I could not pay for the taxi to go to work. With a disability allowance, I would have been able to keep my job.”

In this example, the lack of accessibility of the public transportation system led to prohibitive costs of getting to work which were not compensated by an adequate social protection benefit.

Sometimes, it may be about ordinary goods. Persons with albinism, for instance, may need good quality sunglasses and use significant quantity of quality sunscreen among other things.

Additionally, there are increased needs that are more subtle. For example, there may be a need for a family with a child with disability to relocate to a higher rent area in close proximity to urban centers where services they may require are available.

On the other hand, some extra costs are **disability specific**, for example assistive devices, personal assistance, and some rehabilitation services. Any of these things may be required for a person with a disability to fully participate in family and community life. For example, a man from Vietnam said,

“I have to buy a walking stick to support me. It costs around 120,000 dong (\$5) and it needs to be replaced every six months...Every three years I must replace the prosthetic pieces at a cost of 2.1 million dong (\$99) for the groin piece and 4 million (\$190) for the knee piece. In addition, I must spend approximately 800,000 dong (\$37) per year on bandages and shoes for my disability. I have a health insurance card, but I must pay everything myself.”

This is in a country where the urban poverty line is roughly \$40 per month and the average monthly income is about \$160. Even a relatively moderate disability can thus pose a significant economic hardship in most low- and middle-income countries (LMICs) where there is a strong lack of availability and affordability of assistive devices. Those costs are in addition to other health care needs, both ordinary and disability specific, which can be prohibitive. Indeed, persons with disabilities are significantly more likely to face catastrophic health expenditures than those without disabilities.

Most people with disabilities face a combination of both ordinary and disability specific needs for goods and services. For instance, many persons with disabilities who require personal assistants or interpreters will face much higher cost to access health care or many other services as they will have to pay for the human assistance and their transportation. **The less the environment (transport, infrastructure, services) is accessible and inclusive, the higher those extra costs will be for persons with disabilities.**

The level and type of costs are not static, as the very act of seeking social and economic participation can significantly increase the costs of disability. Indeed, when persons with disabilities stay at home, they have a minimal level of activity, thus lowering their support requirements and can therefore be more able to rely only on family support. If they go to work or seek social participation, they will often require paid support, more transportation and more robust or different assistive devices, among other costs.

In most LMICs, accessibility and provision of reasonable accommodations are low in general and even more so in informal sectors where the majority of economic opportunities lie. There is little to no publicly funded support to cover disability related employment accommodations and persons with disabilities have to bear most of those costs, which are often prohibitive for them.

Human assistance related costs are often the most impactful. Globally, family members provide the essential part of needed support. This situation is exacerbated in LMICs, where very few publicly funded formal support services exist, especially for those requiring extensive support and for children with disabilities. This impacts both the autonomy of persons with disabilities and the economic opportunities for their primary providers of support.

As mentioned earlier, **persons with disabilities and their families do not only face disability related expenditures but they also tend to earn less income.**

First, persons with disabilities facing multiple barriers to employment, including from previous discrimination in the education system, have lower employability and so tend to earn less. Additionally, households have to forego income as family members reduce or stop work to provide support. In South Africa, a study showed that households with children with disabilities earn on average 30% less than households with children without disability. In addition, children in households with adults with disabilities might also have to provide care at the expense of their education. Having a parent with a disability increases the likelihood that children aged from 7 to 16 years will never attend school by 25 percentage points in the Philippines and 13 percentage points in Uganda (UNESCO, 2010).

These extra costs prevent people with disabilities from participating in society and thus greatly affect their quality of life and undermine their chance to escape from poverty and marginalization.

Not accounting for these extra costs undermines the effectiveness of social protection policies in diverse ways:

- **As poverty measurements rarely account for disability related cost, there is an underestimation of the socio-economic vulnerabilities of persons with disabilities.** Similarly, poverty targeted and means tested programs which do not factor disability related costs in their eligibility thresholds exclude many persons with disabilities and their families who actually have a standard of living below the set thresholds. In addition, benefits designed to bring persons or households to a certain standard of living have to be increased or complemented by other benefits to cover disability related costs.
- **Not recognizing that the act of seeking and retaining work can raise disability extra costs can undermine efforts to promote economic empowerment.** This is magnified greatly if the receipt of social protection benefits is contingent, as it is in many countries, on the perceived inability to work.

One of the key challenges for social protection systems is to measure those costs and identify the best way to cover them. After explaining different ways to measure these costs, this paper then addresses how social protection programs can best incorporate them.

METHODS FOR MEASURING THE EXTRA COSTS OF DISABILITY

A variety of approaches for measuring the extra costs of disability exist. According to Tibble (2005), these methods fall into four categories. The first is the subjective approach which asks people to list the extra expenditures they feel they need to participate equally. The second approach -the comparative approach - asks people with and without disabilities what their expenditures are and sees where the differences emerge. The third, which is the standard of living approach, attempts to statistically determine those differences instead of asking directly. The final approach, as described by Tibble, is the budget standards approach, which is similar to the subjective approach except respondents are not asked what their extra expenditures would be, but what goods and services they would need. The researchers then price those items. These approaches can be subsumed in the three methods:

Goods and Services (GS)

The most direct way of estimating how much people with disabilities are spending because of their disability is to simply ask them. This is known as the *Goods and Services (GS)* method. An interviewer asks a respondent with a disability to list the amount, type, and value in currency of all expenditures necessitated by their condition. This approach falls closest to the category of comparative methods as designated by Tibble (2005) where people with disabilities are asked to list their expenses in addition to what they would spend if they did not have a disability.

Designing a quantitative questionnaire to capture these extra expenditures is challenging for a few reasons:

1. There are potentially many different ways that extra expenditures may arise. It is difficult to list all possible items on a survey form

2. The nature of expenditures will be affected by the type of the disability and the local context
3. People may choose options that are in excess of what is needed to participate on an equal basis as people without disabilities. For example, a person who needs accessible transportation could buy a bus pass (if buses are accessible and available), a basic model accessible van, or a luxury model, depending on their circumstances
4. Some expenditures may be missed because people do not associate them with the extra costs of disability. As an example for this we can take the issue mentioned above about needing to settle in a high cost neighborhood because of accessibility concerns.

A study in South Africa (SADSD, 2015) that measured the extra costs of disability using the GS approach conducted a series of qualitative interviews in order to create a list of possible extra expenditures. They identified costs related to basic consumption, care and support, and access to essential services and participation. Data were collected from 12 expert groups of people with nine different disability types, including 206 adults with disabilities and 62 caregivers of children with disabilities. The interviews continued until there were no additional issues or costs mentioned. This was achieved for some groups (e.g. deaf-blind people), but not for others (e.g. parents of children with disabilities) because of time constraints, which revealed varied and complex nature of the sources of extra costs.

Table 2 Extra Costs of Disability in South Africa (SADSD, 2015)

EXTRA COSTS OF DISABILITY IN SOUTH AFRICA		
<i>(1 rand is about .066 US dollars)</i>		
Diversity of persons with disabilities	Disability related out of pocket cost in rand	
	Min	Max
Blind persons	545	4344
Deaf persons	155	14030
Persons with deafblindness	407	14703
Person with physical disability		
moderate level of support needs	700	> 3500
high level of support needs	2300	>7000
Persons with intellectual disability with moderate support needs	321	3852
Persons with uncontrolled epilepsy	945	4215
Persons with autism		
high functioning	197	3663
low functioning	522	3663
Persons with psychosocial disabilities	26	4200

Expert group sessions worked towards a consensus of the type and range of costs facing people with different types of disabilities. Price estimates emerging from group discussions were checked for accuracy. Total out-of-pocket (or direct) extra costs are shown in Table 2, listed by type of disability. Note that the range of estimated costs varies widely, not just by the type of disability, but even among people with the same type and basic degree of disability. These

differences depend on the type of family support they can get, the barriers in their environment and their level of participation.

The minimum amounts reflect the costs of people who face less barriers to access essential services or those with lower levels of participation, using mostly support from families. The maximum reflects higher costs related to paid support (sign language interpreters or personal assistance) and to transport (for the persons and their assistants) required in order to overcome barriers to accessing essential services and/or seeking social and economic participation. For example, as shown in table 2, a blind person in South Africa can be expected to need between 545 (\$52) and 4,344 (\$416) extra rand per month, A person with a physical disability in constant need of assistance, between 2,300 (\$220) and 7,000 rand (\$671), but a person with a physical disability requiring minimal assistance as little as 130 rand per month. For comparison, the poverty line in 2015 was 992 rand per person per month and the minimum wage 4,355 rand.

Another important issue to note when using the GS method for determining the extra costs of disability is the fact that this method only measures what is spent, not what is needed for equal participation. The GS approach shows also the diversity of socio-economic situations of persons with disabilities. Indeed, people may spend less than what is needed for several reasons:

1. They are income constrained and are making a choice between essential items like rent and food and the goods and services needed for full participation
2. The goods and services they require are not available for purchase in their location
3. They are unaware of goods and services available to enable their increased participation
4. There is discrimination within the household, and household members in charge of family resources are choosing to not purchase needed items.

Therefore, another approach used in measuring the extra costs of disability is the *Goods and Services Required* (GSR) method.

Goods and Services Required (GSR)

This method expands on the GS method by collecting information on what expenditures would be needed to enable a person with a disability to participate equally in society. Tibble refers to this as a subjective method where people answer in terms of expenditures, and as a budget standards approach when they list needed goods and services to which researcher subsequently applies prices.

A potential added complication in making such an estimate in low- and middle-income countries is that needed goods and services may not be available, either in the country as a whole or in particular locations within that country. In those cases, estimates must be made as to what the price of those goods and services would be if available. Those prices will vary even within a country by region, and, of course, will change as the markets for those goods and services develop.

Also, for the GSR method it will be important to rely on a subset of respondents with higher expertise in support needs. In fact, a sample of respondents may very well have to be supplemented with such experts because many people, especially those who are poor or who

live in remote areas, may not be aware of what types of support and assistive technology is possible.

Some results from a study in New Zealand (where needed goods and services and their prices are available) that used the GSR are shown below (DRC, 2008). Figure 1 shows the diversity of the added weekly costs needed for persons from different disability groups in relation to different activities. It is important to note that the costs captured in that research did not include the disability related cost associated with workplace accommodations or the cost of healthcare services, which would have significantly increased overall costs.

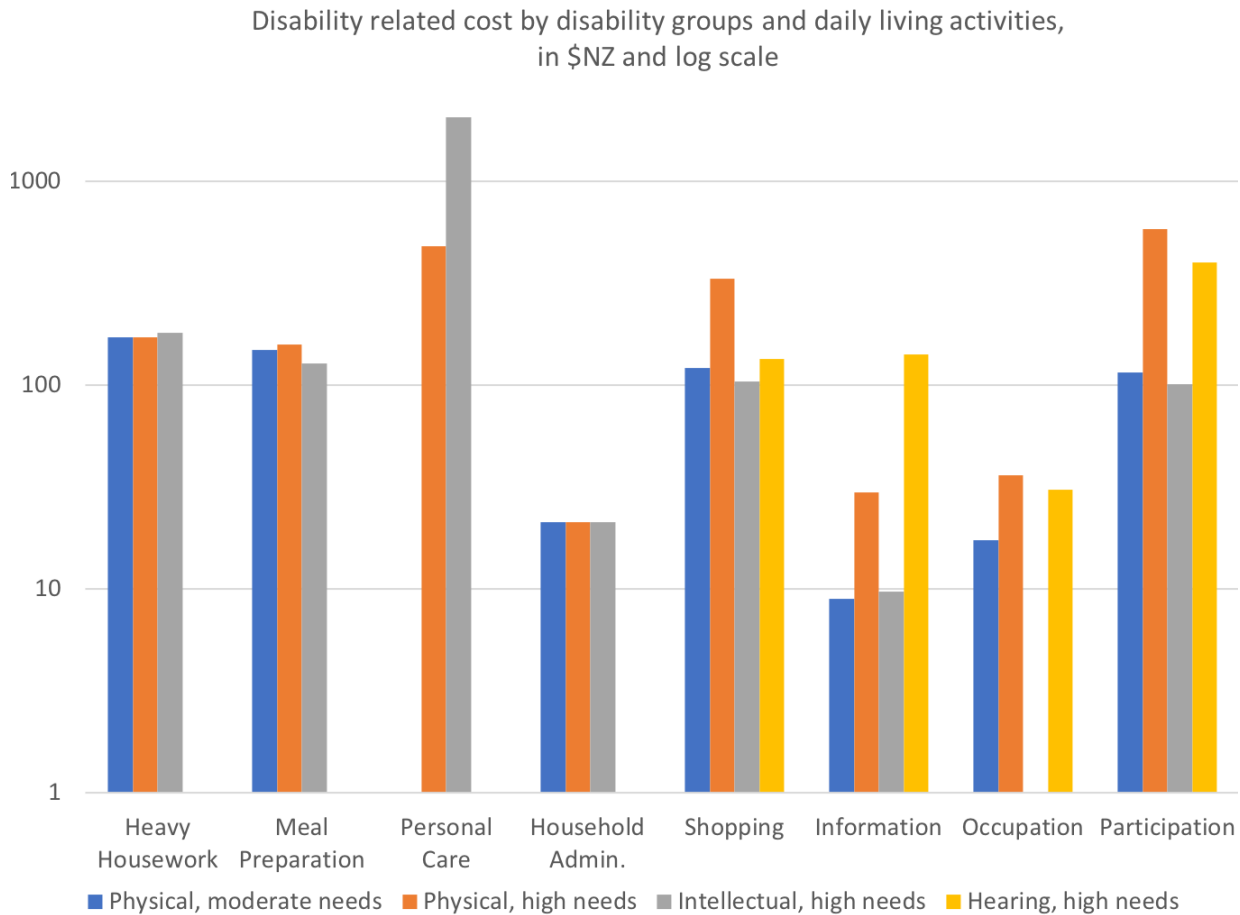


Figure 1 diversity of disability related cost (DRC, 2008)

Figure 2 shows the total and composition of costs (equipment, support and transport) for different disability groups with significant diversity. As mentioned earlier, for most groups support is the primary source of costs, but it still varies tremendously between groups. It is also important to note that for 7 groups out of 10 the weekly disability related costs are higher than the weekly New Zealand minimum wage (see graph below).

These estimates would likely change for other countries depending on the environmental context and the relative prices of goods and services. However, the facts that cost differ dramatically by type and degree of disability and that the majority of costs would fall under the support category would probably remain.

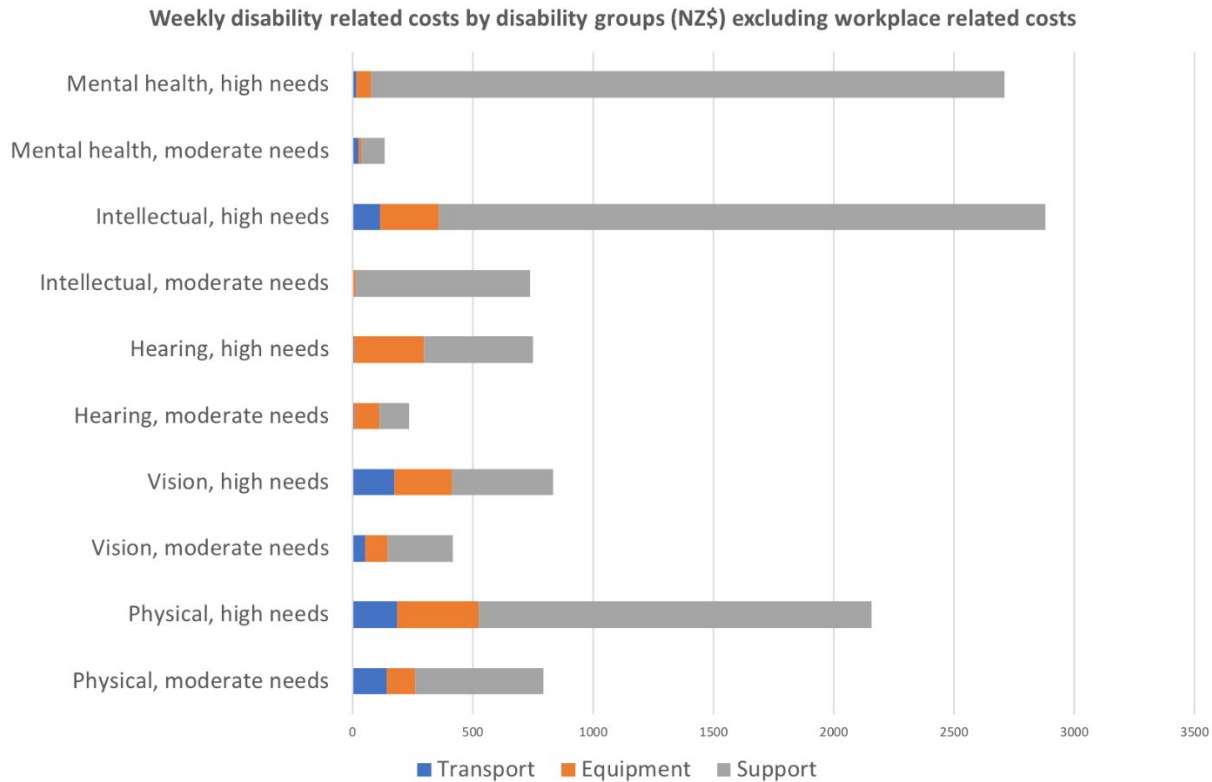


Figure 2 Weekly disability related costs by disability groups (DRC, 2008)

Standard of Living (SOL)

The final approach for measuring the extra costs of disability is the *Standard of Living (SOL)* approach. This approach is not based on intensive interviews to establish actual expenditures – either made or needed – but makes statistical inferences from regularly collected data on income and wealth. It is the most frequently used method and may have led to some misunderstandings.

The basic idea behind the SOL approach is that two families that have very similar characteristics: where they live, the income they have, household size, etc. should have similar expenditures.

Therefore, we would expect for them to have on average the same level of wealth. If one of those families has a disabled household member and one does not, then the household containing a member with a disability will have extra expenses.

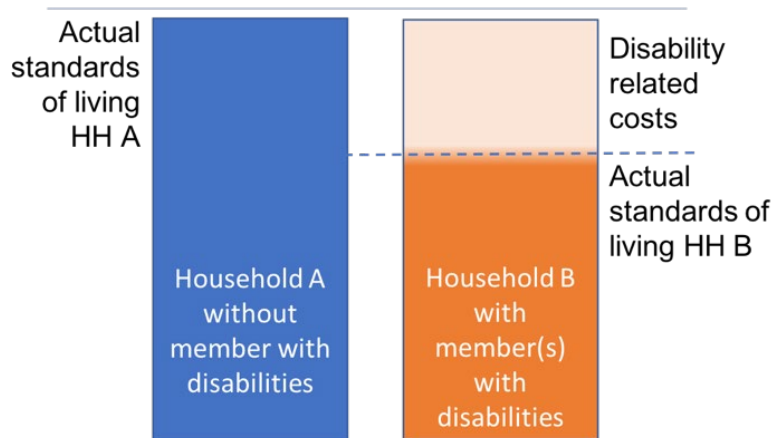


Figure 3 Standard of living approach

Those extra expenses will decrease their wealth; hence, the gap in wealth between two similar families whose only difference is that one has a member with a disability and the other does not, is considered to be a result of those extra costs. In the SOL method, the wealth gap is typically measured by an asset index. In low-income countries this would include non-financial assets, such as a motorbike, radio, refrigerator, bicycle, etc.

One advantage of the SOL method is that if questions identifying people with disabilities are included in a country's Household Income and Expenditure Survey (HIES) or Living Standards Measurement Study (LSMS), then all the information necessary for such an estimate is available. This makes it a very inexpensive methodology which can be done on a regular basis. A number of studies employing this method find that the extra costs of disability generally range from 12 to 40 percent of a country's average wage.

Table 3 presents results of the nine papers that use the SOL approach. Given the great variance in income across countries, the results are reported as a percentage of income.

Table 3 SOL estimates of the extra costs of disability

SOL ESTIMATES OF THE EXTRA COSTS OF DISABILITY			
Reference	Country	Age Group	Percentage of Average Income, by category of people
Brana, J-P., & Anton, J-I. (2011)	Spain	Age >17	Moderate 40%, Severe 70%
Braithwaite, J., & Mont, D. (2009)	Bosnia Vietnam	All ages	14% 9%
Cullinan, J., Gannon, B., & Lyon, S. (2011)	Ireland	All ages	All 23%, Moderate 30%, Severe 33%
Cullinan, J., Gannon, B., & O'Shea, E. (2013)	Ireland	Age >65	40%
İpek, E. (2019)	Turkey	All ages	9.1 for those not working 14.6 for those working
Loyalka, P., Liu, L., Chen, G., & Zheng, X. (2011)	China	All ages	Adults: 8% to 43% Children: 18% to 31%, Moderate 3% to 116%, Severe 14% to 158%.
Mont, D., & Cuong, N. V. (2011)	Vietnam	Age >5	12%
Saunders, P. (2007)	Australia	Age >65	All 29% Moderate 30%, Severe 40%
Zaidi, A., & Burchardt, T. (2005)	UK	Age >65	Mild 11%, Moderate 34%, Severe 64%

However, the SOL approach has a number of drawbacks. First, like the GS method it only accounts for what is spent, not what is needed for full participation. But there are additional concerns:

1. It provides no information on the types of goods and services needed
2. The results are sensitive to what assets are included in the asset index. Constructing such an index in an ad hoc manner could be very misleading

- Household survey samples are often not large enough to make different estimates by type of disability, and GS and GSR methods (and one SOL study using a very large sample) suggest big differences in extra costs depending on the type of disability.

It is also important to note that disability related expenditures estimated with SOL seem to be lower in LMICs compared to high-income countries, most likely due to the lower availability of goods and services and lower purchasing capacity.

Indirect and opportunity costs

Not only do persons with disabilities and their families have to spend more to achieve the same standards of living and participation but they also tend to earn less. While some issues relate to long lasting effect of discrimination in accessing education, some are more directly related to discrimination in the labour market as well as foregone revenue from household members quitting or reducing work to provide support and care to the person with disability.

Comparing income levels is critical as it can help identify the level of opportunity costs faced by those households that could be compensated by social protection. Such assessment has been conducted, for instance, in the 2015 South Africa study (ibid) on disability costs. It revealed that households with children with any kind of disabilities and those with adults with significant disabilities earn markedly less, most likely because of the need to provide support and care.

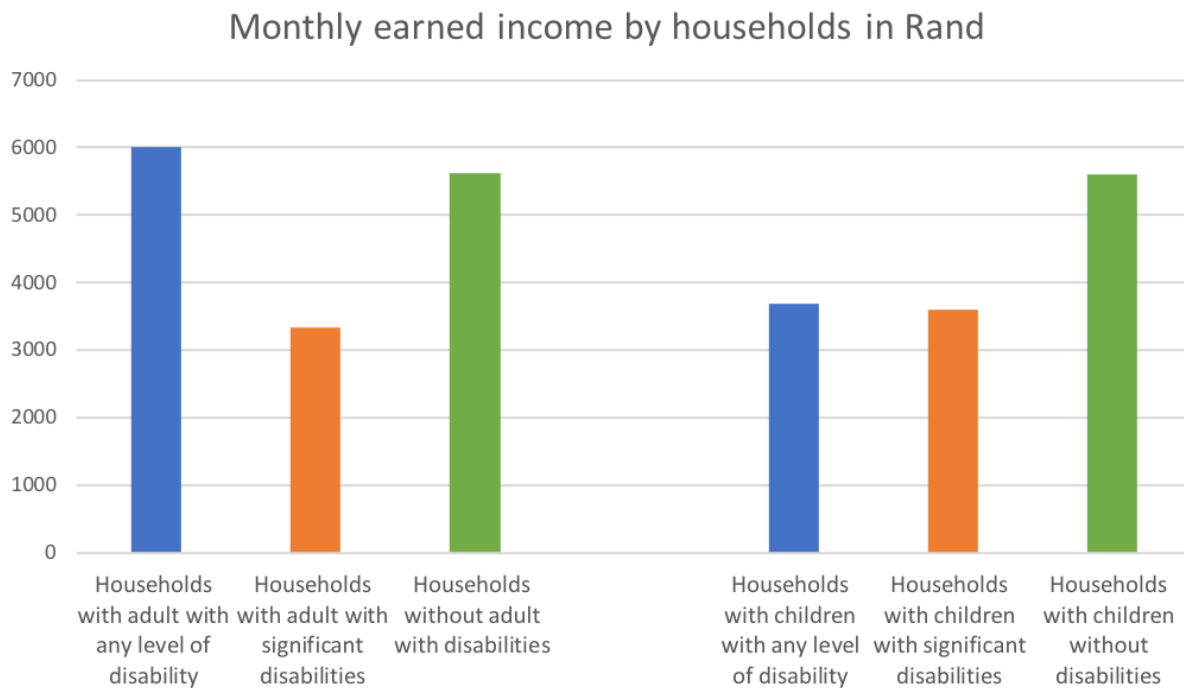


Figure 4 Monthly earned income by households (SADSD, 2015)

Only the households with a person with a sight impairment earned more than households without members with disabilities which is likely related to the fact that a significant part of persons with moderate sight disabilities, acquired as they aged, have education and work career on par with others.

Monthly earned income of households by type of functional difficulties, any level.

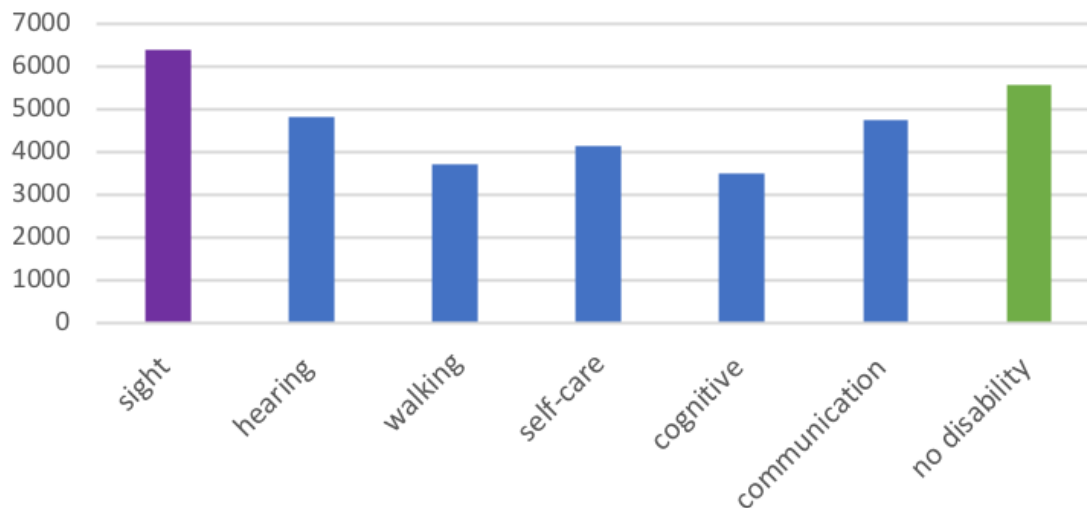


Figure 5 Monthly earned income by type of functional difficulties (SADSD, 2015)

Different methods of estimating disability related costs for different purposes

The question remains: which method of accounting for extra costs should be used for designing social protection programs?

Three main issues are important for the design of social protection systems:

- Current economic impact of disability related barriers and lack of support for persons with disabilities and their families
- Different expenditures that persons with disabilities and their families are facing in addition to or instead of other common goods and services compared to persons without disabilities
- The costs and expenses that persons with disabilities and their families would have to cover to achieve equal participation.

The answers to these questions can help design social protection benefits and inform planning and development of needed services.

The SOL approach is the method most often used and cited because it is an inexpensive approach, once disability identification questions are placed on household surveys. It informs the current economic impact of disability on households, especially if combined with a measure of differences in earned income between households with and without persons with disabilities. This can help estimate more accurately their living conditions or exposure to poverty. Indeed, accounting for those extra costs significantly increases the poverty estimates for households with

persons with disabilities, for instance (using SOL method alone): from 18% to 34% in Cambodia, 17.6% to 23% in Vietnam and 21.1% to 30.8% in Bosnia Herzegovina (ILO, 2017).

However, as stated earlier, its sensitivity to how asset indices are constructed, and the fact that it only measures what is spent, not what is needed, and provides no information on what people are spending their resources on, greatly limits usefulness of this approach for design of social protection schemes.

The GS method provides more details about the diversity of current disability related expenditures and can help assess whether current social protection and other interventions provide relevant support.

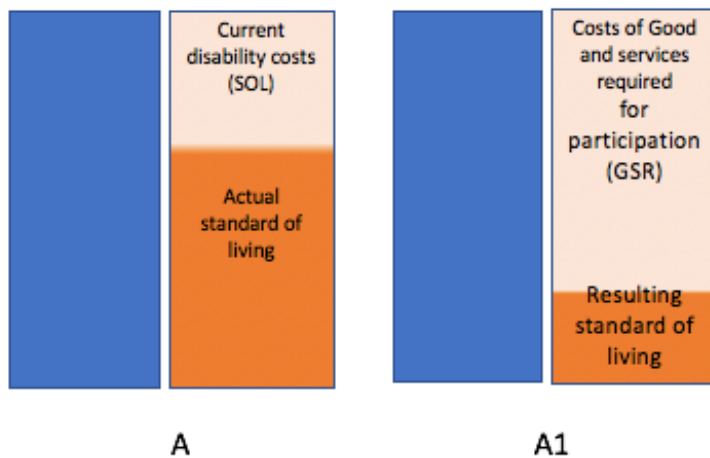


Figure 6 SOL vs GSR methods

The GSR method is the only one that actually estimates what is needed for equal participation. Many persons with disabilities living in poor and non-poor households do not receive the support they require. Figure 6 shows that if household where actually spending what is required for participation their resulting standard of living would be much lower. The SOL method only assess the impact on standard of living of what household can afford

not what is required. However, the GSR method is a more expensive and time-consuming process and cannot generally be done on a scale that allows for disaggregation by geographic area or other personal characteristics. Nevertheless, conceptually the GSR method is the most appropriate for designing social protection programs as it will highlight what the most needed and costly services are (those individuals who would be prime candidates for in-kind benefit provision) and a range of what additional costs are needed. It also would serve as an evidence base for why those expenditures are needed.

As stated earlier, the more inclusive the environment, the lower the extra costs paid directly by persons with disabilities and their families. For example, if sign language interpretation is available everywhere then it no longer must be covered by the individual. By identifying amounts of money that they must be spent to overcome particular barriers in the environment, the GS/GSR methods could be used to identify and prioritize public investments needed in accessibility and inclusion in order to minimize those extra costs.

Using all three methods in a country could be very useful. For example, using the GS and SOL methods on the same population can serve as a check on the SOL approach to see if it aligns well with GS estimates, or at least the level of costs SOL seems to capture. If it does align, then we can have more confidence in using the SOL method to look at differences in various subpopulations and the influence of various confounding factors which would be impossible with the smaller samples associated with the GS approach

The GS and GSR method together could show to which extent the money spent corresponds to money required depending on (a) the availability of goods and services in different regions or (b) household income and other characteristics, such as education. That is to say, what are the barriers preventing GS expenditures from reaching GSR levels for the diversity of persons with disabilities.

Additionally, if a clear relationship between the SOL and GS/GSR estimates could be established, then the more frequently produced SOL estimates could be used to monitor the level of extra costs in between GSR estimates. The latter will most likely be done on a much less frequent basis given the resources needed to conduct a GS and GSR study. New SOL estimates can be generated with each new round of regularly scheduled household surveys.

Table 4 Use of different methods for estimating disability related costs

KEY QUESTIONS	WHICH METHOD?	RELEVANCE FOR SOCIAL PROTECTION
What is the current economic impact of disability related barriers and lack of support for persons with disabilities and their families?	SOL method and measure of differences in income earned; GS method	Assess more accurately standards of living and exposure to poverty and vulnerability
What are the different expenditures facing persons with disabilities and their families in addition to or instead of other common goods and services compared to persons without disabilities?	GS method	Assess relevance and adequacy of current interventions for the diversity of persons with disabilities
What are the costs and expenses that persons with disabilities and their families would require to achieve equal participation?	GSR method	Define the best combination of support in cash, services as well as concessions; prioritize investments in service delivery and barrier removals

IMPLICATIONS FOR THE DESIGN OF SOCIAL PROTECTION PROGRAMS AND SYSTEMS

Different countries have adopted diverse approaches. In many OECD countries, social protection systems offer both income security and coverage of extra costs through a combination of cash transfers, direct service provision and concessions such as tax exemption, discounts, free transportation cards, etc. Benefits also often include adequate coverage of healthcare expenditures. Few low- and middle-income countries have developed such comprehensive systems although many have developed several building blocks of such a system: Vietnam, South Africa, Brazil, Thailand or Fiji among others. Very few, however, have studied the actual disability related costs faced by persons with disabilities and their families.

Different ways exist to incorporate disability extra costs in the design of social protection programs. Doing so impacts those programs in at least three fundamental areas:

- Setting the income/consumption threshold for qualifying for programs in means tested and poverty targeted programs
- Defining adequate level of benefits to compensate the extra costs of disability
- Defining the most cost effective and context relevant combination of different instruments to cover those costs (e.g., cash transfers and in-kind benefits).

For those three issues two questions are cross cutting:

- How to take into account the diversity of costs faced by different groups of persons with disabilities?
- Do we consider the expenditures and costs that people are currently facing or those that they would face should they seek equal basic participation?

Attempts to take into consideration disability related cost in means test

On its most basic level, social protection programs are designed to ensure a minimum level of wellbeing. Thus, eligibility determination rules and benefit levels for many social protection programs are often set according to a conception of what that minimally acceptable level of wellbeing is, given social standards and fiscal resources. Therefore, the primary goal of social protection cannot be achieved without incorporating disability extra costs into program design, since households with disabled members require those costs in addition to what other households require to achieve the same standard of wellbeing.

Often eligibility income thresholds and benefit levels are pegged to the national poverty rate or some fraction or multiple of it (that rate being based on requirements for a healthy diet, adequate food and shelter, etc). In other words, program parameters are derived from the cost of necessities. However, as we have seen, to maintain the same level of wellbeing as persons without disability, persons with disabilities need to cover disability specific goods and services in addition to items like food and shelter. Therefore, a household with a member with disability

does not have the same standard of living as a similar family without a member with disability for a given level of income or consumption.

If those extra costs of living with a disability are not accounted for in means-tests or poverty scores, then many people with disabilities who are effectively living below the poverty line will be excluded from those programs. The same is true if benefit levels are set without regard to those extra costs. The extent to which those benefits lift people with disabilities above the targeted standard of living will be lesser than for people without disabilities. Therefore, it is essential that social protection programs incorporate the extra costs of living with a disability into their design.

When it comes to accounting for the extra costs of disability in social protection programs there are a number of approaches. The following scenarios are simplified, stylized options that are meant to demonstrate some of the issues involved. They assume there is a current social assistance program with an established income/consumption eligibility threshold, and that a government now wants to modify that policy to incorporate the extra costs of disability.

Disability adjusted means test threshold

Building on figure 3, Figure 7 shows how not accounting for the extra expenditures being made by households with disabilities undermines the effectiveness of a means test. The blue bars represent households without household members with disabilities, and the orange bars those with members with disabilities. In both cases, A, and B, households have the same level of income but those with persons with disabilities have a lower level of wellbeing as measured by the SOL method.

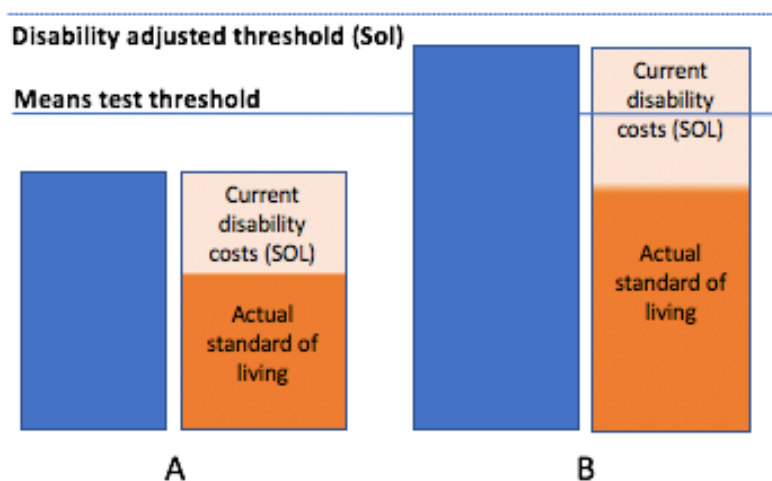


Figure 7 Impact of SOL on means test threshold

To fully measure the impact of disability on the standard of living, however, it would be important also to incorporate the impact of foregone revenue. Let's imagine that a person in household A with a member with a disability had to reduce or stop working to provide support. Their household might actually have had a higher income level in B if a family member was not needed at home to provide such support.

Indirect costs aside, if the means test was to be set at the same level for all, then the household with persons with disabilities in case B would be denied the support while its actual standards of living would still be below the regular threshold; hence the need arises for a disability adjusted threshold, which could be set using the SOL method. Such an approach however does not reduce the inequalities between households with and without disabilities at the same income level. The effective poverty gap for those with disabilities will remain higher.

This could be compensated by the provision of a higher benefit or a disability top up for eligible households with a person with disabilities such as in Zambia or Indonesia (PKH program).

Guaranteed annual income (GAI)

Under a GAI program, benefit amounts are adjusted so each household can reach a guaranteed standard of living, defined by some monetary amount that represents what is considered the minimum acceptable level of wellbeing. Once again, to reach this standard of living disabled households need to have their extra costs covered. For each household, their benefits would cover the gap between their income and the desired standard of living.

Moldova is one country that takes this approach using equivalent scales (Carraro, 2014). Each person in the household is assigned a weight based on their relative additional costs to the family. For example, the head of household would be assigned a weight of 1. The second adult in the household would receive a lower weight, for example 0.8, since the additional costs of adding another person to the household is lower due to economies of scale. Children would receive a lower weight because their consumption needs are less, for the sake of argument let that equal 0.6, then the sum of these weights for all household members represents the relative needs of the household.

So, for example, a family with a mother, father and three children would have a household weight of: $1 + 0.8 + 3(0.6) = 3.6$. If a GAI was set at \$1000 per 'person', this family's GAI would be \$3600.

To adjust for their extra costs of living, the weight of a person with a disability in this scheme would be set at a level to compensate for the estimated extra costs. For example, say it was estimated that a person living with a disability experienced extra costs equal to 50 percent of what a non-disabled person needs. Now, assume that the father in the above example had a disability, so his weight was not 0.8, but instead $0.8 + 0.5$, or 1.3. Then the household weight would be: $1 + (0.8+0.5) + 3(0.6) = 4.1$ and the family's GAI would be \$4100 instead of \$3600. The size of the added weight for a person with a disability would have to be based on the analysis from household income and expenditure surveys with SOL methods.

A GAI policy would provide grants equal to the difference between a family's income and their calculated GAI. While this ensures that all households receive the GAI, it does not equalize the outcomes between households with and without disabilities that are above the GAI. A disabled household with an income above their GAI will have a lower effective standard of living than a non-disabled household with that same level of income.

Beyond Averages: addressing the diversity and reality of disability related costs

The above approaches do not consider the goods and services required for participation but only compensate for part of the current economic impact of disability on households. Such measures may level the standard of living at the household level without having significant impact on the participation of individual members of household with members with disabilities who are not getting the support they require for participation. They also take a monolithic approach to disability related costs, based on average estimates. Finally, they do not take into

consideration intra-household dynamics that could lead to a person with disability being deprived in a non-poor household.

Considering the diversity of disability related costs

A complicating factor is that not all households with disabilities face the same extra costs. As shown in the previous section of this paper the variance in extra costs experienced by persons with disabilities is quite large. There is indeed a vast heterogeneity of costs faced by different persons with disabilities not only in level but also by type of costs. The SOL method provides an average of estimated additional expenses across households. If the sample is large enough, those average costs can be estimated separately for those with moderate as opposed to those with severe functional difficulties. Studies referred to earlier using either GS or GSR methods in New Zealand and South Africa (ibid) found that disability related costs could be 10 times higher for groups with high support needs compared to those with moderate ones. Variations in standards of living would increase even more if opportunity costs and difference in earned income between households were considered.

To truly support inclusion, there is a need to account for these heterogeneous costs.

This approach is more in line with the Convention on the Rights of Persons with Disabilities in that the goal of the program is to equalize the ability to participate in society. If all people have the full costs of living with a disability covered, they are on a more equal footing to be full members of the community.

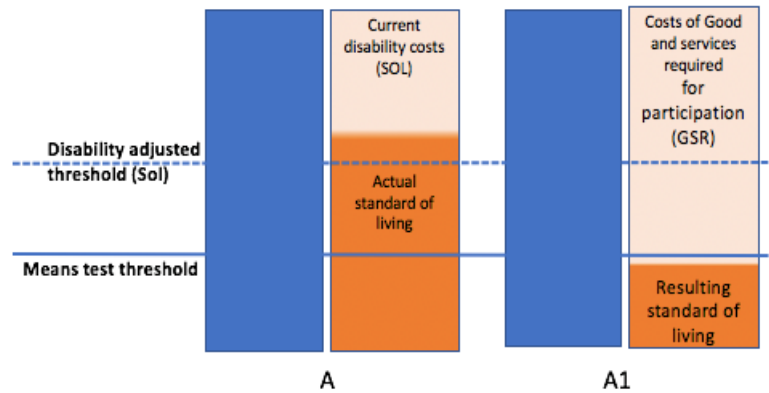
The size of extra costs depends on a variety of factors including not only the type and degree of disability but also the local environment. Another complicating factor is that the extra costs of disability can vary based on whether a person is working or not and to which extent their employer covers disability extra costs related to work. A study from Turkey (Ipek, 2019), for example, shows that the extra costs facing people with disabilities who were working were in average 14.6 percent of households' income compared to only 9.1 percent for those who were not working, presumably because transportation, support or interpretation costs were higher.

Many LMICs such as Nepal, Vietnam or Georgia among others have different levels of support for different levels of disability. This is based on the assumption that people with severe disabilities will have both higher costs and will be less likely to engage in work and earn income.

Considering the reality of costs of goods and services required for basic participation

The 2015 South Africa study (ibid) shows that disability costs required for participation would on average be at least three times the poverty line for all people with disabilities. The New Zealand study (ibid) showed that it would be at least equivalent to the minimum wage. This shows that poverty targeting or even means test of disability related support is not in line with the reality of most persons with disabilities and their families.

Figure 8 expands on Figure 7 by looking at the implication of including the actual cost of goods and service required, and challenges the very idea of a means test in relation to support for covering disability related costs. Case A1 shows households with and without disabilities with income way beyond means test threshold. Accounting for the



disability related costs from a GSR perspective, the household with a person with disabilities would still be below the standards of living associated with this initial threshold as well as with the disability adjusted one based on SOL methods.

Considering the concentration of income in top deciles, along with the flat income and consumption distribution across the rest of the population in most low and middle income countries, a person with significant disability living in a household belonging to the 6 or 7th income decile would still not be able to afford the support they require for equal basic participation without jeopardizing the household basic standard of living.

Some countries have tackled this issue by providing a universal disability allowance (e.g., Mauritius, Fiji, Georgia) or by having a very high means test, for example in South Africa where the threshold is set at around 5 times the poverty line. However, this does not address as such the issues of adequacy of benefits and the diversity of costs.

Towards comprehensive, inclusive and adequate coverage of disability related costs

One of the issues that is sometimes difficult to grasp for policy makers and advocates alike is that for most people with significant disabilities, cash allowances provided in LMICs rarely cover basic consumption, let alone disability related costs that can be several times higher than the benefit provided, especially for those with high support requirements.

In addition, in most LMICs, there is no distinction between disability related cash transfers for income security and for coverage of extra costs. Often there is only a single disability cash transfer, which is frequently conditioned on being considered unable to work. Recent studies have shown that, in the absence of complementary measures, disability allowances generally only support basic household consumption and not disability related costs.

However, if disability benefits are universal and compatible with work, then those with a higher level of income might be able to use the disability allowance for some disability specific costs. In addition, if combined with poverty assistance and old age pensions, it can provide such support for most persons with disabilities eligible.

Nevertheless, considering the wide diversity of costs and the level of those related to human support, one cash transfer alone is not sufficient. A more comprehensive approach is required.

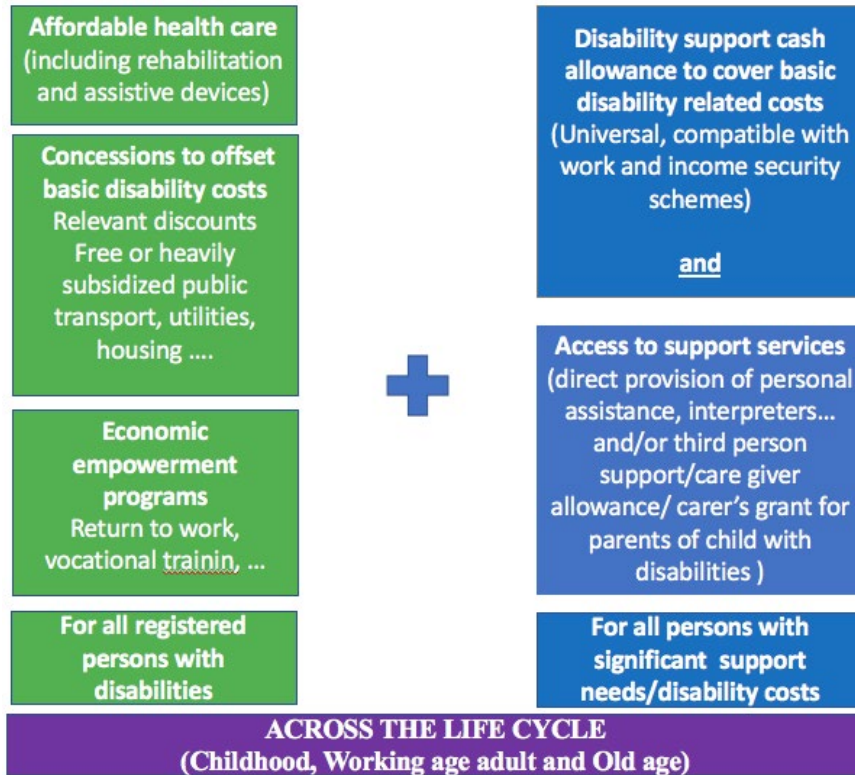


Figure 9 Combination of schemes to cover disability related costs

It is important to consider the diversity of costs facing persons with disabilities: higher consumption of ordinary services and goods, disability specific goods and services as well as human support and assistance.

In addition to basic income security schemes aiming at ensuring food security and shelter among others, a way to approach adequacy and recognize diversity of persons with disabilities is to develop a progressive combination of support such as:

- *Free or heavily subsidized health care* including (re)habilitation and assistive devices
- *Universal disability support cash allowance* which could cover some of the basic disability related costs, especially increased consumption of ordinary goods and services and some of the lower-cost disability specific goods and services. This could be granted to persons with significant disabilities including children with disabilities, working age adults and older persons. As this allowance is supposed to cover basic disability costs, it should be compatible with work and other support aiming at basic income security such as old age pension.
- *High levels of human assistance and support* such as personal assistance or sign language might have to be covered either by a specific third person support allowance, care giver allowance for parents of children with disabilities, a voucher system or direct provision, as they are very costly. This kind of assistance would be granted only to persons who are assessed as requiring such support. It can also be provided to older persons with disabilities in addition to their old age pension (South Africa, Mauritius..).
- *Concessions* such as free public transport, discounts for taxis, social housing or other types of relevant and meaningful concessions in order to offset or cover costs of some ordinary services and goods as well as some of the higher-cost disability specific goods and services. This could be granted to all persons with disabilities who are officially recognized as such.

It is important to note that those measures complement income security schemes (including unemployment benefits, disability pension, old age pension and poverty assistance) and economic empowerment programs.

As mentioned, different countries are developing some of these building blocks. In Nepal, for instance, there are four different colored cards related to different levels of disability with some concessions for all levels, but a cash allowance is provided only for the two highest levels. However, the adequacy of the benefit is very low. In Fiji, persons with significant disabilities who work or who live in a household benefiting from poverty assistance schemes are eligible for the disability allowance and support for public transportation and access to some assistive devices.

Excluding medical expenditures the majority of extra costs are due to human support needs, including personal assistants and assistive devices. For example, the predominant cost item in New Zealand was for support, which primarily consisted of personal assistance. Table 4 shows that across the board personal assistance represents the majority of extra costs.

Table 5 Percentage of disability related costs dedicated to human support (DRC, 2008)

Percentage of disability related costs dedicated to human support (New Zealand)		
	Moderate support needs	High support needs
Physical	67	76
Vision	65	50
Hearing	53	60
Intellectual	98	88
Mental Health	72	97

Few LMICs have developed support services, but some provide specific third persons support or care giving allowance. For instance, in Mauritius all persons with significant disabilities benefiting from the disability allowance as well as persons receiving old age pensions are eligible for an additional allowance if they require high levels of human assistance.

In some LMICs where a significant part of the population has low income cash benefits covering the full range of costs, including personal support, could create tension in the community. Families could put significant pressure on persons with disabilities to use that income for other purposes. In-kind support either through vouchers or direct provision seems to be a more workable alternative.

More and more countries are moving towards providing expensive assistive devices directly either through universal health coverage packages or social affair services. Few are investing in direct service provision of human support such as in Fiji for sign language interpreters or Thailand for personal assistance.

The disadvantage of providing in-kind services (like personal assistance) is the administrative complexity and cost, and also people's autonomy if they feel their needs are different than the in-kind support being provided. However, the advantages are a more efficient targeting of benefits to those who need them, and a possible reduction of fraud both in terms of whether a person qualifies for benefits, and fraud of family members appropriating benefits for needs other

than the needs of household members with a disability. The reason is that, unlike cash, personal assistance or other such services or devices are only of use to people who truly need them.

Covering support needs through in-kind benefits would reduce the variation in the remaining extra costs and allow for fewer under- or over- cash payments meant to cover them. However, it should be kept in mind that the financial and social costs of such in-kind benefits could vary widely according to the place where a person lives. Employing a personal assistant in a city, for example, might be much easier than in a rural area. Some research shows that people in small villages are uncomfortable with having neighbors as their personal assistants. Also, stigma can sometimes be attached to being a personal assistant, which makes finding one difficult. Importing a person from another location could be expensive or not even feasible. One option is to hire family members as personal assistants. This, however, can impose indirect costs on the family if the pay for being an assistant is lower than their alternative earnings. On the other hand, it could increase family income. Obviously in accounting for family income in the means test for any program the earnings from being a personal assistant to a family member should be excluded.

Similarly, a voucher for assistive devices may either be insufficient in an area where they are not available or very costly if they must be purchased and brought in from elsewhere (which, of course, many families would not have the capacity to undertake). A guarantee to cover any cost of such a device might prove expensive. Therefore, if the in-kind route is taken it is incumbent upon the government to develop an infrastructure for delivering such goods and services, both to ensure access and to minimize the expense of persons with disabilities.

CONCLUSION

Interest in accounting for the extra costs of disability in social protection programs is growing, but countries generally lack the information necessary to accurately and confidently account for such costs. Three such methods have been put forward to do this.

Extra costs can vary dramatically depending on the type and level of functional difficulties and support requirements, the environment and the type and level of participation of persons with disabilities. It will vary by country context – or even by regional areas within a country. Therefore, the final recommendations should be considered:

1. **Social protection programs should account for the extra costs of disability.** Clearly the extra costs of disability are significant and can stand in the way of equal participation for people with disabilities, push them in poverty or prevent their escape from it. This includes the extra costs associated with seeking and retaining work or accessing education. Policies should be constructed to remove those barriers.
2. **There are different approaches to estimate disability related extra costs, which can be used for different purposes**
 - a. The Goods and Services Required (GSR) method should be applied for determining the extent and structure of benefits designed to cover the extra costs of disability. The GSR method can highlight not only what level of resources are needed, but also their purpose. This can be used to design context-relevant combinations of cash transfers and in-kind benefits, including support services.
 - b. The Good and Services (GS) and GSR methods should be used together for more detailed exploration of the impact of extra costs. The GS and GSR method can be used together to uncover where the gaps in spending are.
 - c. The Standards of Living (SOL) method is potentially useful for nationally representative studies on the impact of disability on socio-economic outcomes and for adjusting means test threshold for mainstream schemes. Assessment of indirect costs should complement the SOL method when determining impact of disability on standards of living of individuals and households. These methods also require much fewer resources and can be re-calculated on a more frequent basis. Countries should explore if SOL methods can be soundly pegged to GS/GSR estimates, and thus contribute to these purposes.
3. **Disability adjusted means test threshold could be adopted in relation to mainstream social protection schemes** with the *understanding that it will contribute to reducing exclusion errors but will not equalize impact of those schemes for persons with disabilities and their families compared with those without disabilities.*
4. **Categorical cash benefits, such as disability support allowance should be provided to contribute to coverage of disability extra costs.** The types of expenditures needed by people with disabilities vary widely, depending on the context of the place where a person lives and the type of disability they have. The flexibility provided by cash benefits is important to make sure all needs are met. Considering the significant impacts of both direct and indirect costs

on the vast majority of persons with disabilities and their families, especially those with significant disabilities, it should be provided through universal categorical benefit or, if means test is politically unavoidable, on a affluence test basis but not poverty targeted.

5. **Health care costs, including (re)habilitation and assistive devices should be covered for all persons with disabilities.** Considering that persons with disabilities tend to have greater health care needs and are much more likely to face catastrophic expenditures, it is imperative to provide them with adequate health care coverage.
6. **To address the diversity of costs and tend towards adequacy, extra costs should be covered by a combination of cash and in-kind benefits.** Costs can vary dramatically by type and degree of disability. Consequently, a single one-size-fits-all cash benefit will either greatly fall short of fulfilling some people's needs or be prohibitively expensive, if it is designed to make sure all needs are met. Therefore, a combination of cash transfer, meaningful concessions and services is essential. For major sources of extra costs, like personal assistance, support could be provided through an additional benefit, such as caregiver grant or in-kind, through direct service provision or vouchers. To reduce the costs of in-kind benefits, delivery mechanisms for needed goods and service should be developed.

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