

Estimating the Extra Costs for Disability for Social Protection Programs

ADVANCED, UNEDITED DRAFT (AUGUST 2022)

Authors: Daniel Mont, Alex Cote, Jill Hanass-Hancock, Lena Morgon Banks, Vlad Grigorus, Ludovico Carraro, Zachary Morris, and Monica Pinilla-Roncancio

This paper is a revised and expanded version of a background paper written by Daniel Mont and Alex Cote as 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 was co-financed by Leonard Cheshire in the frame of the DFID funded I2I project.











Table of Contents

LIST OF TABLES	3
LIST OF BOXES	3
LIST OF FIGURES	3
EXECUTIVE SUMMARY	4
INTRODUCTION	5
THE DIVERSITY OF DISABILITY-RELATED COSTS	6
METHODS FOR MEASURING THE EXTRA COSTS OF DISABILITY	8
Goods and Services	9
MethodLimitations and Interpretation	
Goods and Services Required	
Method	
Limitations and Interpretation	
Standard of Living (SOL)	
MethodLimitations and Interpretation	
The different purposes of the approaches to measuring disability related costs	
THE ROLE OF PARTICIPATORY METHODS IN ESTIMATING EXTRA COSTS	
INCORPORATING DISABILITY EXTRA COSTS INTO THE DESIGN OF SOCIAL PROTEC	
PROGRAMS AND SYSTEMS	
Integrating disability related cost in qualifying thresholds for means tested households	
targeted programs and adjusting program benefits	
Beyond Averages: addressing the diversity and reality of disability related costs	33
Considering the diversity of disability related costs	
Need for Multiple Programs	36
CONCLUSION	40
ANNEX A – Technical Note on Standard of Living Method	
	45

LIST OF TABLES

- Table 1: Extra Costs of Disability in South Africa
- Table 2: Use of different methods for estimating disability related costs
- Table 3: Percentage of disability related costs dedicated to human support

LIST OF BOXES

- Box 1: Goods and Service Methodology
- Box 2: Costs for persons with disabilities in New Zealand, using the Goods and Services Required methodology
- Box 3: Goods and Services Required Methodology
- Box 4: Standard of Living Methodology
- Box 5: Standard of Living Estimates and Unmet Needs
- Box 6: Participatory Approach to Estimation and Policy Development: Example from South Africa.
- Box 7: Ongoing Efforts to Estimate Extra Costs of Disability

LIST OF FIGURES

- Figure 1: Diversity of disability related costs
- Figure 2: Weekly disability related costs by disability groups
- Figure 3: Standard of living for households with and without disabilities with the same income
- Figure 4: Poverty rate s among people with disabilities adjusted for Extra Costs of Disability
- Figure 5: Standard of Living Method versus Goods and Services Required
- Figure 6: Impact of Standard of Living Method measure on means test threshold
- Figure 7: Standard of Living Method vs. GSR adjustments for extra costs
- Figure 8: Average monthly income by percentile in Brazil (2019) in reals

Figure 9: Combination of schemes to cover disability related costs

Figure A1: Standard of living, income, and disability, with fixed extra costs

EXECUTIVE SUMMARY

People with disabilities face extra costs of living, both those specific to disability, such as assistive devices and personal assistance, and general expenses, such as medical care and transportation. Without accounting for these costs, the impact of disability on socioeconomic outcomes will be underestimated. Furthermore, if social protection programs are not designed with these costs in mind, they will not be structured in a way that promotes equal participation and protection from poverty.

Several ways exist to measure these extra costs, each with its own uses, advantages, and disadvantages. This report explains these methods, how to implement them, their uses, and limitations. All these methods, however, show the large impact of disability on economic wellbeing.

The Standard of Living method uses data from Household Income and Expenditure Surveys and similar instruments, to generate estimates of the average extra expenditures made by households with disabilities. This method can be used to examine the current economic impact disability is having on households. It has the limitation, though, of not identifying what specific goods and services are being purchased, nor does it estimate what is needed for full participation. People may be spending less than what is needed because they face income constraints, they are unaware of goods and services that could help them, those goods and services are not available where they live, or because of discrimination within the household.

The Goods and Services method is more resource intensive to implement but has the advantage of identifying what goods and services people with disabilities are purchasing and how that differs by the type and degree of disability. However, the sample sizes are generally too small to make nationally or even regionally representative estimates, and even if they are sufficiently large, probably not big enough to disaggregate expenditures by various characteristics. The Goods and Services method also has the same limitation as the Standard of Living method in that it measures what is being spent, not what is needed for full participation.

The Goods and Services required method does estimate what particular goods and services are needed for full participation, and so is well suited for designing social protection programs with that purpose in mind. However, it does not estimate the current economic impact of disability on households.

All methods suggest the impact of disability on households is substantial, but both the Goods and Services and Goods and Services Required method reveal that there is great variance in costs by type and degree of disability. Moreover, that a significant proportion of those experiencing large costs lie in a few areas, such as personal assistance. A conclusion to be drawn is that a one size

fits all cash transfer is not well suited to effectively and efficiently meet the needs of people with disabilities.

The report ends with the following series of recommendations.

- 1. Social protection programs should account for the extra costs of disability.
- 2. The different approaches to estimate disability related direct extra costs can be used for different purposes
- 3. Disability adjusted means test thresholds and amounts could be adopted in relation to mainstream social protection schemes
- 4. Categorical cash benefits, such as disability support allowance should be provided to contribute to coverage of disability extra costs.
- 5. Health care costs, including (re)habilitation and assistive devices should be covered for all persons with disabilities.
- 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

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, where disability "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others."

For persons with disabilities to avoid exclusion and access essential services, they must have not only the resources needed by those without disabilities, but additional spending and other forms of supports and accommodations to overcome these barriers.

In addition to having to spend more to achieve the same standards of living, persons with disabilities also tend to earn less income due to barriers in employment and opportunity costs incurred by family members providing support. ² Together, those additional expenses and forgone income constitute the disability related costs which prevent them from seizing economic opportunities and achieving a similar standard of living and participation.³ This creates a vicious circle that social protection can help break with a well-designed combination of schemes.⁴

¹ Convention on the Rights of Persons with Disabilities, Preamble, Section (e)

² WHO/World Bank (2011) World Disability Report

³ Mitra, S., Palmer, M., Kim, H., Mont, D., Groce, N. (2017). "Extra costs of living with a disability: A systematized review and agenda for research," Disability and Health Journal

⁴ Cote, A. (2021) Disability Inclusion and Social Protection, Chapter 19 Schuring, E. and Loewe, M. (eds.) Handbook in Social Protection Systems, Elgar

Social protection programs, to be inclusive, need to account for these extra costs. Different countries, due to both different levels of resources and different approaches to social protection, may need to incorporate extra costs in different ways, but in every case, it is essential for fulfilling the goals of the CRPD and the "leave no one behind" mandate of the UN's Sustainable Development Goals.

The paper covers several critical elements required for social protection systems and programs to adequately consider disability-related extra costs. The first part explains the diversity of disability-related costs. The second part presents current methods to assess and measure these costs and the issues they raise. Finally, the last part shows how social protection systems can incorporate the different disability-related costs into their design.

THE DIVERSITY OF DISABILITY-RELATED COSTS

Disability-related costs are diverse. Their type and magnitude depend on the type and severity of persons' functional difficulties, their health conditions and support needs but also critically on the level of accessibility and inclusiveness of their environment. Finally, these costs will be related to someone's level of participation. For example, if a person would like to work, they may need to incur extra costs to do so (e.g., transportation to the workplace or workplace accommodations), which are related to the type and severity of their disability.

These extra costs fall into two categories:

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 related devices and services. Some costs may be covered by social protection system (for example provision of care services) that are not included in direct costs.

Indirect costs. These include lower levels of earnings for persons 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.

This paper focuses on estimating the *direct costs* of disability and how those estimates can inform the design of social protection programs. Henceforth, when the costs of disability are mentioned, they will refer to those extra expenditures (direct costs), and not the indirect costs.

However, it is essential to keep in mind that there is often a trade-off between direct and indirect costs regarding human assistance. A family can reduce direct costs by providing support instead of hiring an assistant, which may lead to foregone income and raise indirect costs. Any additional income a family member could earn by going into the labor market would then be offset by the cost of purchasing the human assistance their family member requires. While this paper focuses on estimating the direct costs, the relationship between indirect and direct costs must not be forgotten.

Some of these direct costs are from the higher consumption expenditures of ordinary goods and services that all people may use but are of higher necessity for people with disabilities. Health care and transportation are prime examples. Sometimes, it may be about ordinary goods. Persons with albinism, for instance, may need good quality sunglasses and use a significant quantity of quality sunscreen among other things. Additionally, there are increased needs that are more subtle. For example, a family with a child with disability may relocate to a higher rent area to be in closer proximity to urban centers where required services are available. Others might have health needs that require greater heating costs in the winter or more expensive specialized food diets. On the other hand, some extra costs are disability specific, for example assistive devices, personal assistance, and some rehabilitation services⁵.

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 to fully participate in society. And the greater the costs, the more likely people with disabilities may go with unmet needs for required goods and services.

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. However, staying at home or reducing participation to avoid costs of disability can lead to isolation and the failure to reach basic living standards, and higher indirect costs in the future (e.g., loss of income from employment, further decrease in functioning). If persons with disabilities do 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.

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

- Persons with disabilities may be excluded social protection programs as standard meanstested benefits understate the extent of poverty among persons with disabilities. As poverty measurements rarely account for disability related direct costs, they underestimate the socio-economic vulnerabilities of persons with disabilities. Consequently, poverty targeted and means tested programs that do not factor disability related costs into their eligibility thresholds exclude many persons with disabilities and their families who have a standard of living below the set thresholds.
- Regular benefits from social protection programs may provide a lower standard of living for persons with disabilities due to the extra costs they face. Social transfer programs that

⁵ Mitra, S., Palmer, M., Kim, H., Mont, D., Groce, N. (2017). "Extra costs of living with a disability: A systematized review and agenda for research," Disability and Health Journal

provide benefits at an equal level for persons with and without disabilities are not allowing them to maintain equal standards of living. To do so, benefits must be increased or complemented by other benefits to cover disability related costs. In addition, because disability-related costs vary depending on the type and degree of disability, social protection mechanisms need to be adjusted to fit the support costs of a particular disability category.⁶

Social protection may fail to support economic empowerment of persons with disabilities. By not recognizing that the act of seeking and retaining work can raise disability-related expenses, social protection payments can be insufficient to support persons with disabilities obtaining employment. This failure can be magnified if the receipt of social protection benefits is contingent on the perceived inability to work or if disability benefits can be lost if the person starts working or earning above a defined threshold, which is the case in many countries.

METHODS FOR MEASURING THE EXTRA COSTS OF DISABILITY

Three approaches exist for measuring the direct extra costs of disability.⁷

- The first approach, known as the Goods and Services (GS) method, asks persons with disabilities to identify their extra expenditures.
- In the second approach, persons with disabilities are asked to list the extra expenditures they would need to participate equally, which in the CRPD means fulfilling social roles such as education, employment, civic participation, and family life. This method is referred to as the Goods and Services Required (GSR) approach.
- The third method, known as the standard of living (SOL) approach, determines differences in expenditures between households with and without members with a disability using data on income, assets, and other household characteristics collected in standard household surveys.

The differences between these measures and the reasons they may diverge are discussed below, but there is one important distinction which is paramount: the difference between expenditures that are currently being made and expenditures that are necessary to obtain some standard of participation, which in the CRPD means fulfilling social roles such as

⁶ Hanass-Hancock, J. and McKenzie, T.C. (2017). People with disabilities and income-related social protection measures in South Africa: Where is the gap? *African Journal of Disability*, 6, 1-11, South African Department of Social Development (2015) Elements of the financial and economic costs of disability to households in South Africa, Results from a pilot study.

⁷ Tibble, Mike. *Review of existing research on the extra costs of disability*. Leeds: Corporate Document Services, 2005, Mitra, S., Palmer, M., Kim, H., Mont, D., Groce, N. (2017). "Extra costs of living with a disability: A systematized review and agenda for research," Disability and Health Journal, Mont, D, and Cote A, "Considering Disability Related Extra Costs in Social Protection," Inclusive Social Protection for the Empowerment of Persons with Disabilities, Background Paper #2, UNPRPD, 2020

education, employment, civic participation, and family life. Crucially, methods based on current expenditures are likely to underestimate the direct costs of disability.

Also, it is important to keep in mind that when it comes to care and support for persons with disabilities and their families there is often a trade-off between direct and indirect costs. A family can reduce their direct costs by providing support themselves instead of hiring a carer or personal assistant, but this may lead to their foregone income, raising indirect costs. Alternatively, any additional income the family member who provide care and support could earn by going into the labor market would then be offset by the cost of purchasing the human assistance their family member requires. While this paper focuses on estimating direct costs, the relationship between indirect and direct costs must not be forgotten.

Goods and Services

Method

The Good and Service method's primary goal is to estimate the range of expenses linked to disability and how they break down by the types of goods and services purchased. These additional expenses can be assessed directly, by asking a respondent with a disability to list the amount, type, and value in currency of all expenditures they feel are necessitated by their impairment to overcome disabling barriers. This approach can use either qualitative or quantitative methods. For example, a purposive qualitative sample could be used to identify the range of expenditures and how they break down by the types of goods and services purchased. Alternatively, if the goal is to generate population estimates of disability related expenditures, then of course a much larger random sample is needed to generate reliable statistics of the average amount of particular disability related goods and services are being purchased

Additional expenditures with the Goods and Services approach can also be measured indirectly, by comparing expenditures between people with and without disabilities in certain categories where people with disabilities are likely to incur additional expenses (e.g., health, transport). For example, excess health expenditures relative to people without disabilities can be an indication of disability-related health costs. Typically, this approach to Goods and Services is incorporated into quantitative surveys

Designing data collection tools such as survey questionnaires or interview guides to capture these extra expenditures is challenging since as there are potentially many different types of extra expenditures. Particularly for surveys, it is difficult to list all possible items on a survey form. Formative research, such as consultations with experts, people with disabilities and Organizations of Persons with Disabilities, are recommended to identify context-relevant costs. It is often helpful to construct data collection tools around what people need to carry out daily activities, such as self-care, work, school, shopping, or various civic activities.

Box 1 provides more detail on carrying out the Goods and Services method.

Box 1: Goods and Service Methodology

- 1) Recruit and train a team of experts A team of experts should be assembled, consisting of members of organizations of people with disabilities and social protection specialists with direct experience with disability related services, the study context, as well as survey design specialists. They should possess expert sector knowledge of various types of disability: physical, cognitive, sensory and psychosocial, and be trained on the purpose of GS, the methodology, and the use to which the results will be put.
- 2) Study design and identifying sample for investigation— The scope and methods of the study should be clearly defined (e.g. are costs being measured directly or indirectly? Qualitatively or quantitatively?). Key to the study design is determining the sample scope and size. For example, if the goal is to assess costs for a wide range of people with disabilities in the study setting, it is important to ensure the sample includes people with various impairment types, genders, age groups, income levels, rural/urban, or other characteristics associated with the costs, knowledge, and availability of goods and services. This can be achieved either through a purposive sample (e.g. obtained using either disability registries and/or a snowball sample starting with members of organizations of persons with disability) or for ensuring sample sizes in a survey are sufficiently powered to identify and then disaggregate people with disabilities with characteristics of interest.
- 3) Identify disability categories/groups for investigation with the disability sector Linked to step 2, it is important to consider which types of disabilities will be investigated (e.g. intellectual, psycho-social, vision, hearing, physical, deafblind); the trained expert group needs to engage with the disability sector and government during the inception phase to identify how the different types and degrees of disability are grouped in the investigation (e.g., hard of hearing and the Deaf) for the presentation of results. For all agreed upon groupings, it is important that the sample is sufficiently robust.
- 4) Develop data collection tools the expert group should develop a data collection instrument (survey, interview guide) relevant to the study design. Tools should ask about expenditures made to achieve a range of activities work, school, housework, shopping, civic participation, etc. It should account for costs occurring monthly, annually or over several years and be able to be broken down per month or year. It should include disability-related goods and services (e.g. assistive devices, personal assistance) as well as general items (e.g. transport, health) where people with disabilities might experience additional spending.

- 5) Data collection All data collection tools should be pilot tested before widescale implementation to ensure they are well-understood and relevant to different respondent groups. Data collectors should be trained in how to provide accommodations to ensure the direct participation of respondents with disabilities in the research. Standard data management procedures should also be followed (e.g. monitoring of data collection, data cleaning and verification, safe and confidential data storage).
- 6) Estimation A range of costs should be estimated for each type and degree of disability identified in step 3, also broken down by major categories, such as assistive technology, personal assistance, health care, transportation, etc.

Example: South Africa

A study in South Africa⁸ (SADSD, 2015) that measured the extra expenditures related to disability using the direct GS approach (before looking at services required) developed an economic questionnaire creating a list of possible extra expenditures, how often these occur and who pays for them. They identified costs related to basic consumption, care and support, and access to essential services and participation. The questionnaire was used by 12 expert groups covering different disability types in adults and children, who collected data of people with nine different disability types, including 206 adults with disabilities and 62 caregivers of children with disabilities. Thereafter the expert groups discussed their findings to build a consensus about the potential range of the extra disability related costs per disability type⁹. Total out-of-pocket (or direct) extra costs from the South African study are shown in Table 1, listed by type of disability

Designing a quantitative questionnaire to capture these extra expenditures is challenging since as there are potentially many different types of extra expenditures, it is difficult to list all possible items on a survey form.

⁸ Department of Social Development, *Elements of the financial and economic costs of disability to households in South Africa. Results from a pilot study.* 2015, DSD South Africa: Johannesburg.

⁹ Department of Social Development, Elements of the financial and economic costs of disability to households in South Africa. Results from a pilot study. 2015, DSD South Africa: Johannesburg, Hanass-Hancock, J., et al., "These are not luxuries, it is essential for access to life" Disability related out-of pocket costs as a driver of economic vulnerability and exclusion in South Africa. AJOD, 2017. 6(0): p. a280.

Table 1: Extra Costs of Disability in South Africa				
	(1 ra	nd is about .066 US dollars)		
Diversity of persons with disabilities	Disability related ou	t of pocket cost in rand		
	Min	Max		
Blind persons	545	4344		
Deaf persons	155	14030		
Persons with deaf blindness	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 Source: SADSD (2015)	26	4200		

Limitations and Interpretation

Estimates of disability-related costs using the Goods and Services approach should be interpreted as what people with disabilities are able to spend with their current incomes on disability-related needs, not the value of all goods and services required to ensure equal participation. The nature of expenditures is affected by many things, leading to the wide range of estimated expenditures. These include:

- Type and degree of disability. Persons with disabilities may have very different functional limitations requiring potentially a vast array of devices, accommodations, or types of support.
- Family support. The capability and willingness of family members to provide support or make accommodations can differ.
- Knowledge and availability. Not all assistive technology and support services are widely
 available. Differences can exist even within a country, and knowledge of the things
 needed to enable participation can also vary based on people's education and experience.
- Affordability. When families are budget constrained, they must make choices even among necessities. Such families may be forced to forego goods or services needed by their household member with a disability, especially high-cost needs.

- Environmental barriers, accommodations, and supports. Persons with disabilities live in
 different environments that have different barriers that must be overcome. Sometimes
 these barriers may be ameliorated by things like accessible transportation or government
 services. Sometimes they may be heightened by things such as rough terrain and poor
 infrastructure.
- Intrahousehold discrimination. Households often make joint decisions on expenditures, or such decisions are made by certain members of the household who may not value the participation of their household members with disabilities.

A key takeaway from studies using the Goods and Services approach is that disability-related costs are highly variable amongst people with disabilities. Consequently, a one-size-fits-all approach like a uniform value social protection benefit is not an effective or efficient option. Further, costs are often severely underestimated using this approach, particularly in settings with high poverty levels and poor access to and knowledge of disability-related goods and services. The minimum amounts in Table 1 can reflect not only the expenditures of people who face fewer barriers to accessing essential services or are mostly using support from their families but also those with lower levels of participation. Consequently, with the GS approach, people with low costs associated with disability may have high unmet needs due to poor availability or unaffordability of costs of needed goods and services. Box 2 further elaborates on this point.

The maximum amounts in Table 1 reflect the experiences of people with disabilities who have likely had better access to required services, and so their higher costs are closer to what would be estimated using the GSR approach (see below). The higher costs are related to paid support (sign language interpreters or personal assistance) and to transport (for the persons and their assistants) required to overcome barriers to accessing essential services and/or seeking social and economic participation. For example, 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 (\$12) per month. For comparison, the poverty line in 2015 was 992 rand (\$95) per person per month and the minimum wage 4,355 rand (\$416). Therefore, after accounting for these costs – even if underestimates of the true costs required – persons at the higher end of disability related expenditures are highly likely to be living in multidimensional poverty and have low participation, unless they have very high levels of income.

The maximum level of expenditures estimated, which are more in line with full participation, is analogous to the standard approach of setting a poverty line. That is, drawing a line that is not based on a basic level of wellbeing but a conception of what is considered a full life, which can vary from country to country based on the local context.

Goods and Services Required

Method

This method collects information on what expenditures would be needed to enable a person with a disability to participate equally in society. In contrast to the Goods and Services method described above and the Standard of Living method which will be described shortly, the Goods and Services Required captures both actual and required costs, including those that are unmet, It primarily uses qualitative methods and purposive samples¹⁰. Of course, the disability community should be included at all stages of project design and implementation. This should occur at the inception phase to ensure buy-in and to incorporate the knowledge of persons with disabilities who directly experience these costs.

Briefly, this method also requires bringing together experts (e.g., service providers, researchers, people with disabilities and Organizations of Persons with Disabilities) to design or adapt an economic question guide including a list of the range of goods and services potentially needed and broken down by various subgroups of persons with disabilities (e.g., by impairment type, age group, work status, gender). Then focus groups of people with disabilities are conducted with different disability groups to gather more detailed information to verify, expand, and modify the initial lists and gather information on what is currently being spent on these items, how often these costs occur and who pays for them. The expert group then adjusts their lists and prices based on focus group discussions and augments their estimates by conducting market research to estimate the costs of needed goods and services that are not currently available.

Box 2: Costs for persons with disabilities in New Zealand, using the Goods and Services Required methodology

Figure 1 shows the diversity of the added weekly costs needed for persons from different disability groups in relation to different activities, based results from a study in New Zealand that used the GSR. 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.

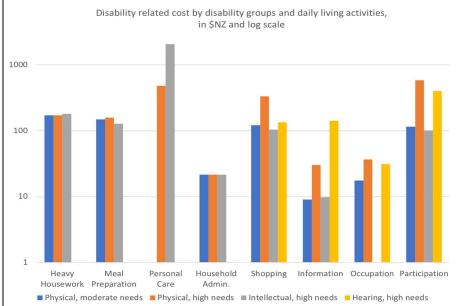
Figure 2 shows the total and composition of costs (equipment, support, and transport) for different disability groups with significant diversity. As mentioned earlier, for most groups support is the primary source of costs, but it still varies tremendously between groups. It is also

¹⁰ A purposive sample is different from a random sample, in that the sample is chosen to explicitly obtain representatives from the groups being examined, to make sure all groups are represented without having a large sample. This allows the analyst to compare the experiences of different groups but does not allow estimates that are representative of the population.

important to note that for seven groups out of 10 the weekly disability related costs are higher than the weekly New Zealand minimum wage (see figure below).

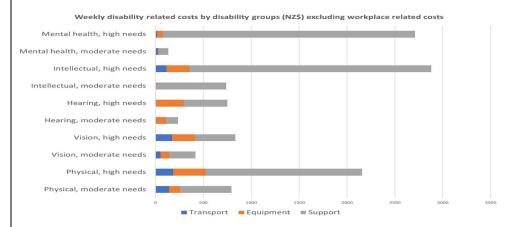
These estimates would likely change for other countries depending on the environmental context and the relative prices of goods and services. However, the facts that cost differ dramatically by type and degree of disability and that most costs would fall under the support category would probably remain.

Figure 1: Diversity of disability related costs



Source: Disability Resource Center, 2008

Figure 2: Weekly disability related costs by disability groups



Source: Disability Resource Center (2008)

The included costs should all be what are incurred by people with disabilities and their households in the study setting, excluding any costs that are currently being borne by the state. For example, if the health system provides partial coverage for rehabilitation services, only the proportion of costs paid by individuals should be included. However, in settings with low investment in disability-inclusive planning, people with disabilities may have to bear costs that would most effectively be covered through public spending (e.g. paying out of pocket for tutors, specialist education resources due to the lack of inclusive education; paying for private transport due to inaccessible public options). These costs to overcome the lack of disability-inclusive public services should be included in the total. Market research may be required to estimate the costs of needed goods and services that are not currently available or for which few people have access to in the study setting.

Box 3 lays out in detail a methodological approach that is based on work that has occurred in several countries. At the core of this methodology is the conception of what is meant by "needed." Needed for what? In generating a range of estimates, it can be useful to agree upon different levels of participation that could be addressed by programs designed to meet that need. In a low-income country one level of participation might simply be for survival. That is, what is necessary to secure life. A level up from that is basic participation which means that the person has the capability of participating in a core set of activities. For children, for example, that would include attending school. One level up from that is equal participation, which would refer to what is needed for persons with disabilities to have, on average, the same opportunities as persons without disabilities living in a similar context. Finally, full participation would refer to having no barriers to fulfilling any social role. What activities fall within these levels of participation will vary from one context to another and must be determined by the expert group. The expert group would also determine the appropriate level of participation for the purposes of the GSR estimation, and the nature of that level of participation should be clearly defined.

¹¹ Estimates have been published in South Africa (South African Department of Social Development (2015) Elements of the financial and economic costs of disability to households in South Africa, Results from a pilot study) and New Zealand (Disability Resource Center (2008). The Cost of Disability: Final Report. Report prepared for the Ministry of Social Development. New Zealand) and various authors of this paper are currently involved in projects estimating these costs in Bangladesh, Georgia, Kenya, and Peru.

¹² Hanass-Hancock, J., et al., "These are not luxuries, it is essential for access to life" Disability related out-of pocket costs as a driver of economic vulnerability and exclusion in South Africa. AJOD, 2017. 6(0): p. a280.

Box 3: Goods and Services Required Methodology (1 of 2)

- 1) Recruit and train a team of experts A team of experts should be assembled, consisting of members of disabled people organizations and social protection specialists with direct experience with disability related services. They should possess expert sector knowledge of various types of disability: physical, cognitive, sensory and psychosocial, and be trained on the purpose of GSR, the methodology, and the use to which the results will be put.
- 2) Identify disability categories/groups for investigation with the disability sector Determine the scope of the sample, such as impairment types (e.g. intellectual, psycho-social, vision, hearing, physical, deafblind) and age group (e.g., children, working age, older adults). The trained expert group needs to engage with the disability sector and government during the inception phase to identify how the different types and degrees of disability are grouped in the investigation (e.g., hard of hearing and the Deaf)
- 3) Draw up initial budgets per disability group the expert group should determine the activities included for various levels of participation in the local context (e.g., going to work, school, partaking in community events). Drawing 'a budget' can be very overwhelming. For this purpose, experts might find it helpful to consult with previous disability economic questionnaires for extra costs (e.g. the South African economic questionnaire). Thereafter the experts will draw up initial budgets for the different levels of participation, considering the range of needs and costs depending on the degree of disability and area of residence (rural/urban). This will include the estimated time spent by family members providing support.
- 4) Develop a Focus Group Guide (per disability group) Based on the activities and items in the budget, the researchers would then construct a field guide or economic questionnaire to elicit information on goods and services used, their cost, the extra time spent by family members and others providing support, unmet needs, barriers faced and the goods and services they need.
- 5) Recruit focus group participants researchers need to recruit participants, as homogeneous as possible in terms of barriers to participation and potentially costs, for the different focus groups per disability type (intellectual, psycho-social, vision, hearing, physical) and levels of support needs; Ideally there should be separate groups for children and adults, but if not possible there should a be a group for parents of children with disabilities, as well as a group of youths with disabilities to account for their special concerns (e.g., respite services, the fact that prosthetics must be refitted more frequently, school-based costs, etc.)
- 6) Focus group discussions Using the field guides, information is then gathered from respondents of each group on what goods and services they use or would need for both basic and full participation and how much they spend on them, whether they are available, how much they believe they would cost (including maintenance) if they are not available, and the quantity of time family members spend providing support. The aim of this FGD is to build a consensus of the range of costs for a specific disability group (type, degree and consensus)

- 7) Initial identification of extra costs The expert panel then should use data from focus group discussions to modify their initial lists of required goods and services for ensuring basic participation and full participation by disability group. The experts will then assign a range of costs to these various items based on both their experience and focus group responses. This will necessarily fall within a range because needs can range depending on the severity of the disability and available accessibility of infrastructure.
- 8) Market research on prices –Some needed goods and services may not be available in the country as a whole or in certain areas (e.g. rural areas, informal settlements). The research team must conduct market research to estimate missing prices or assess the cost of creating the service or supplying the good and narrow the range of estimated prices derived at by the expert group.
- 9) Final GSR calculation The updated prices are then incorporated into the spreadsheets created by the expert group for a final determination on GSR. This includes information on the range of these costs by disability group, disability support needs, survival vs. basic vs. equal participation, and rural vs. urban. These costs are then disaggregated by whether they are goods or services. Some cost may occur monthly, annually or over several years and need to be broken down per month or year. It should include sample lists of goods and services required for children with various types and degrees of disability.

Limitations and Interpretation

The primary limitation of the method is its lack of precision. The wide range of needs, the inability to draw a very fine distinction between levels of participation, the potential lack of knowledge about certain support needs and resources and the need to estimate the cost of unavailable goods and services can lead to a very wide range of estimates. However, the method can be very useful for highlighting that such a range exists and where the largest costs lie. This can help in the design of how to deliver goods and services – whether through the direct provision of high-cost items, such as personal assistance and medical care, concessions in areas where persons with disabilities spend more, such as transportation, areas requiring greater public spending to reduce individual costs (e.g., inclusive education, accessible infrastructure) as well as the need for some cash benefits to cover a wide range of idiosyncratic costs. It also points out the problem of trying to cover these costs with a simple cash benefit. The method is also limited to the identified disability groups, and people with different combinations of disabilities may not be adequately reflected in estimates. It also only captures the final cost of goods and services, not

factoring in the often high costs incurred due to lack of information about and inability to access required items (e.g., spending on inappropriate or unneeded goods and services, due for example to poor referrals). Nevertheless, this type of information can be very useful in motivating and framing the debate about how to begin addressing these extra costs.

Standard of Living (SOL)

The final approach for measuring the extra costs of disability is the *Standard of Living (SOL)* approach.¹³ This approach is based on data that is typically collected in Household Income and Expenditures Surveys (HIES) which are standard and regularly implemented in many countries. These surveys record a long list of expenditures, in detail but they often exclude many disability-specific items. The Standard of Living method makes statistical inferences from differences in the standard of living between household with and without disabilities who have similar levels of income.

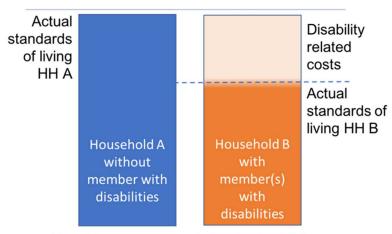
Method

The basic idea behind the Standard of Living approach is that two families, one with a member with a disability and one without, with the same level of income and very similar characteristics (e.g., where they live, household size, etc.) should have similar standards of living, and if they do not that is the result of the extra costs associated with disability.

We would expect two households similar except for the presence of a person with a disability to have on average the same level of wealth, as seen in Figure 4. If one of those households with a person with a disability and one does not, then the household containing a member with a disability will have extra expenses. Those extra expenses will decrease their wealth by not allowing them to build up assets at the same rate as the household without a person with a disability; 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.

¹³ Zaidi, A., & Burchardt, T. (2005). Comparing incomes when needs differ: equivalization for the extra costs of disability in the UK. *Review of Income and Wealth*, *51*(1), 89-114.

Figure 3: Standard of living for households with and without disabilities with the same income



Equal income, unequal standards of living

An advantage of the Standard of Living method is that if questions identifying persons with disabilities are included in a country's HIES, 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. For a more technical explanation of how to carry out the Standard of Living method, see Annex A.

The methodology for the Standard of Living approach is summarized in Box 4. It is useful because it can provide evidence of the correlation of disability and current household wellbeing, and thus demonstrate a potential role for programs addressing the costs of disability and estimating what is needed to achieve different levels of welfare.

Box 4: Standard of Living Methodology

- Include Questions Identifying Persons with Disabilities on HIES. These questions need to be asked of everyone in the household. A growing consensus is that the Washington Group questions are most appropriate.^a
- 2. Choose Standard of Living Measure. The measure that can be readily obtained from most HIES's would be an asset index, which could be constructed using principal component analysis. However, other studies have used other more subjective measures as explained in Annex A.
- 3. Divide sample into types of households. If the sample size allows (as explained below) divide the sample into types of households who might be facing different factors explaining expenditures (e.g., rural/urban, children with disabilities versus older people with disabilities)
- 4. Apply the Standard of Living estimation method. Estimate equation (1) mentioned in the above text and construct a measure of extra costs using the estimated parameter
 - a. Groce, Nora E., and Daniel Mont. "Counting disability: emerging consensus on the Washington Group questionnaire." *The Lancet Global Health* 5, no. 7 (2017): e649-e650

Limitations and Interpretation

Recently many studies using this method have been undertaken, often finding very significant extra expenditures associated with disability. A recent systematic review retrieved 71 studies on disability-related extra costs, of which 18 studies covering 40 countries used the Standard of Living Methodapproach. Estimates of extra costs using the Standard of Living Methodapproach ranged from 5.7% (amongst children with physical disabilities in the UK) to 155% of household income (adult 16+ with disabilities in Norway who are living alone). Cost estimates increased by disability severity. But as discussed further below what is spent may be low not because

¹⁴ Solmi, F., M. Melnychuk, and S. Morris, *The cost of mental and physical health disability in childhood and adolescence to families in the UK: findings from a repeated cross-sectional survey using propensity score matching.* BMJ Open, 2018. **8**(2): p. e018729, Antón, J.I., F.J. Braña, and R. Muñoz de Bustillo, *An analysis of the cost of disability across Europe using the standard of living approach.* SERIEs, 2016. **7**(3): p. 281-306.

¹⁵ Vu, B., et al., *The costs of disability in Australia: a hybrid panel-data examination.* Health Economics Review, 2020. **10**(1): p. 6, Li, J., et al., *Inequalities in standards of living: evidence for improved income support for people with disability.* 2019, Solmi, F., M. Melnychuk, and S. Morris, *The cost of mental and physical health disability in childhood and adolescence to families in the UK: findings from a repeated cross-sectional survey using propensity score matching.* BMJ Open, 2018. **8**(2): p. e018729, Morciano, M., R. Hancock, and S. Pudney, *Disability Costs and Equivalence Scales in the Older Population in Great Britain.* Review of Income and Wealth, 2015. **61**(3): p. 494-514, John, E., et al., *Disability Price Tag 2019.* Policy Report, 2019, Touchet, A. and M. Morciano, *The disability price tag: technical report.* 2018, SCOPE: London, UK, Minh, H.V., et al., *Estimating the extra cost of living with disability in Vietnam.* Global Public Health, 2015. **10**: p. S70-S79.

needs are low, but because needed goods and services are unavailable or too expensive, which is probably why we often find low Standard of Living estimates in poor countries.

When examining studies using the Standard of Living methodology, it is important to keep in mind that we are limited in observing how it is currently implemented, rather than looking at the strength of the theoretical method. The main strength of the method is its ability to compare households with and without members with disabilities within the same instrument while considering different levels of income. Moreover, the method can screen cases where we might require the achievement of certain minimum participation (school enrolment for children, work participation for adults, a certain level of education attainment, etc.).

Currently, some of limitations of the Standard of Living method as have been carried out previously come from the use of datasets that are often incomplete or with relatively small sample sizes. These data sets:

- 1. Have relatively few observations of households with members with disabilities and so the econometric models used compare households that often have different structures. Ideally, we should compare households with same structure and repeat model estimations for each household type (e.g., one person (adult/elderly), couples (adult/elderly), etc.).
- 2. Have incomplete data on expenditures lacking information about disability-specific good and services
- 3. Contain imperfect measures of living standards with little assessment of whether they guarantee inclusion of the person with disability.
- 4. Are often not large enough to make different estimates by type of disability, and GS an GSR methods (and one Standard of Living method study using a very large sample) suggest big differences in extra costs depending on the type of disability. They also miss persons with disabilities that are not covered by the applied disability questions in the survey (e.g., people with epilepsy or internal organ function disorders) or if they do not have an inclusive design and therefore cannot collect data from persons with disabilities (e.g., deaf participants if no sign language is available).

Another line of analysis using the Standard of Living method, which sample size often does not allow, is to estimate extra expenditures separately by income quartile. Since costs might be estimated lower when needs are unmet, it would be useful to see if the costs incurred go up with income. This could be the case as richer households have better access to goods and services and more discretionary income. Even if not, estimate by quartile could give a clearer indication of disability extra costs as a percentage of income.

These limitations could be addressed with a large enough sample and attention to the design of the instrument. However, apart from these limitations the Standard of Living approach has several drawbacks.

- As with the Goods and Services method, it only estimates what is spent, not what is needed.
 So, while addressing those costs may close gaps in household standards of living between
 those with and without disabled members, it does not address what is needed for people
 with disabilities to fully participate in society, especially, unlike the Goods and Services
 method, it provides no information on the types of goods and services needed
- 2. The results are sensitive to the type of standard of living index used and how it is constructed, for example what assets are included in an asset index. Constructing such an index in an ad hoc manner could be very misleading. Also, in most cases the first component of the PCA explains less than 10 per cent of the variance, this means 90 per cent is not explained by the asset index.¹⁶
- 3. Because discrimination can occur within a household, there is no guarantee that a person with a disability in the household is enjoying the same standard of living as others. This relates to the broader point that since Standard of Living method is done at the household level, no intra-household inequalities are observed.

What the Standard of Living method can do is show the current economic impact, on average, on households because of current expenditures related to disability. This can help more accurately describe 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 Standard of Living method alone): from 18% to 34% in Cambodia, 17.6% to 23% in Vietnam and 21.1% to 30.8% in Bosnia Herzegovina¹⁷ or from 32% to 42% in Mongolia and 38.5% to 52.9% in Ghana¹⁸. Adjusting poverty lines by the additional costs generated from Standard of Living approaches documented in the review mentioned earlier increased the proportion of households with members with disabilities who were living in poverty by 2 to 18 percentage points.¹⁹ Figure 5 shows the difference in poverty rates in the US when extra costs are accounted for using different poverty thresholds.²⁰ Adjusting the standard poverty line by disability costs would raise the estimated poverty rate of persons with disabilities from 24% to

¹⁶ Poirier, M.J.P., Grépin, K.A. & Grignon, M. Approaches and Alternatives to the Wealth Index to Measure Socioeconomic Status Using Survey Data: A Critical Interpretive Synthesis. *Soc Indic Res* **148**, 1–46 (2020). https://doi.org/10.1007/s11205-019-02187-9

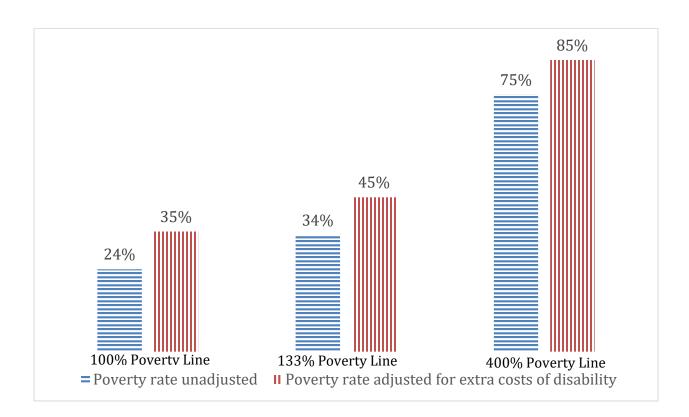
¹⁷ ILO. (2017). World Social Protection Report 2017–19: Universal social protection to achieve the Sustainable Development Goals; page 66-73 International Labour Office – Geneva.

https://www.adb.org/publications/living-disability-mongolia-progress-toward-inclusion, Asuman, D., Ackah, C.G. Agyire-Tettey, F. Disability and Household Welfare in Ghana: Costs and Correlates. *J Fam Econ Iss* **42**, 633–649 (2021). https://doi.org/10.1007/s10834-020-09741-5

¹⁹ Morris, Z.A. and A. Zaidi, Estimating the extra costs of disability in European countries: Implications for poverty measurement and disability-related decommodification. Journal of European Social Policy, 2020. 30(3): p. 339-354, Palmer, M., J. Williams, and B. McPake, Standard of living and disability in Cambodia. The Journal of Development Studies, 2019. 55(11): p. 2382-2402, Morris, Z.A., et al., The Extra Costs Associated with Living with a Disability in the United States. Journal of Disability Policy Studies, 2020: p. 10442073211043521.
²⁰ Morris, Zachary A., and Asghar Zaidi. "Estimating the extra costs of disability in European countries: implications for poverty measurement and disability-related decommodification." Journal of European Social Policy 30, no. 3 (2020): 339-354.

35%. When a more generous threshold – four times the poverty line – 75% of persons with disabilities fall below it, and if extra costs are accounted for 85% of persons with disabilities live below this threshold.

Figure 4: Poverty rates among people with disabilities adjusted for Extra Costs of Disability (source: Morris, et al. (2020))



The different purposes of the approaches to measuring disability related costs

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

- The Standard of Living approach is often used and cited because it is an inexpensive approach once disability identification questions are placed on household surveys.

- 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.
- However, the GSR method is the only one that 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.
- Table 2 summarizes the key questions on extra costs and which methods would be most appropriate that are elaborated on in this section.

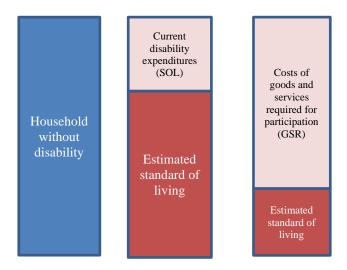
Table 2: Use of different methods for estimating disability related costs

KEY QUESTIONS	WHICH METHOD?	RELEVANCE FOR SOCIAL PROTECTION
How does income differ amongst persons with and without disabilities? Are persons with disabilities more likely to be living in households with income below the poverty line?	A straight comparison of incomes between households with and without disabilities not accounting for extra costs	Assess exposure to poverty and vulnerability according to national definitions.
How much are persons with disabilities spending on direct costs of disability? When taking these expenditures into account, how many people with disabilities are living below the poverty line?	SOL or GS	Assess more accurately standards of living amongst people with disabilities
What are the different expenditures incurred by persons with disabilities and their families?	GS method	Assess current interventions for the diversity of persons with disabilities and determine where others are needed
What are the costs and expenses that persons with disabilities and their families would require to achieve equal participation?	GSR method	 Determine the adequacy of existing measures Define the best combination of support in cash, services as well as concessions Prioritize investments in service delivery and barrier removals

-

- Figure 5 shows that if households were spending what is required for participation their resulting standard of living would be much lower even then what it is when current expenditures – as estimated by the Standard of Living Methodmethod – are accounted for.

Figure 5: Standard of Living Method versus Goods and Services Required



It is very important when interpreting results from the Standard of Living Method to remember that these are estimates of actual expenditures and not needed expenditures. A low estimate does not necessarily mean that needed expenditures are low, but in fact that there may be significant unmet needs, as Box 5 explains. That means, the act of topping up social protection benefits by Standard of Living Method estimates could reenforce the gap between subpopulations who currently have different levels of access to disability related goods and services.

Box 5: Standard of Living Method estimates and unmet needs.

The Standard of Living Method and GS approaches both provide estimates of the amount of out-of-pocket disability-related expenses people with disabilities incur. These approaches, however, only estimate what is spent and not necessarily what is needed for many people with disabilities to participate. Indeed, many people with disabilities, particularly those in low-and-middle income countries, are likely to require many goods and services to participate but that are unaffordable, unavailable, or unknown to them. This unmet need is lost in the Goods and Services and Standard of Living estimates. For example, people with disabilities are estimated to incur just 8% more in expenses, on average, in Ethiopia, Tanzania, Nigeria, Liberia, and Namibia (Mont, Goodman, Morris, Nasiir (2022)), yet, across 15 OECD countries, it was recently estimated that adults with disabilities incur, on average, 44% more expenses to obtain the same standard of living (Morris & Zaidi, 2020). These lower estimates in low-and-middle income countries are likely indicative of the high degree of unmet need that exists for those with disabilities in these contexts. This is important not just for cross-national comparisons as it also suggests the need for sub-analyses of the heterogeneous population of people with disabilities within countries. For example, people with disabilities in high-income countries but from underserved communities with fewer resources are also likely to incur lower disabilityrelated costs but have greater unmet need. As Mitra et al., (2017, 9) note: "Finding low estimates for extra costs is not necessarily a positive signal regarding the wellbeing of persons with disabilities."

The Goods and Services required method, which focuses on needs, is a new method that is still undergoing development internationally. It is more expensive and time-consuming than the Standard of Living analysis when disability data already exists in HIES. However, when comparing it to detailed national disability surveys that attempt to document all expenditures and ask about unmet needs it is in fact cost effective. Conceptually, though, the Goods and Services Required method is the most appropriate for designing social protection programs as it highlights the most needed and costly services and the prime candidates for in-kind benefit provision, as well as a range of what additional costs are needed. It also can serve as an evidence base for why those expenditures are needed.

Using all three methods in a country could be very useful. For example, using the Goods and Services and Standard of Living Methods on the same population can serve as a check on the Standard of Living Method approach to see if it aligns well with Goods and Services estimates. If it does align, then we can have more confidence in using the Standard of Living 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 Goods and Services approach.

The GS approach could also be used to identify the list of items that should be included in a HIES to be able to make direct estimates of disability specific expenditures. Of course, each person will need different things, but there are basic things that should be included that would cover most

costs. With a large enough sample, the estimated costs should be close to the average costs of persons with disability.

In addition, if the items identified in the Goods and Services method were added to the hundreds of items already included in HIES's it would be possible to construct expenditure variables by type of expenses -- disability specific items, health care, food, housing, transportation, etc. – and compare those expenditures between households with and without disabilities, even across different household structures.

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 Goods and Services Required levels for the diversity of persons with disabilities.

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

THE ROLE OF PARTICIPATORY METHODS IN ESTIMATING EXTRA COSTS

A key feature of both the Goods and Services and Goods and Services Required approach is the participatory nature of the process. Both methods involve assembling teams of different types of stakeholders – persons with disabilities, parents of children with disabilities, professional service providers, and policymakers – to arrive at a common framework for conceptualizing disability and come to agreement on a variety of items.

Both approaches require answering important questions:

- How persons will be divided by type of disability in the creation of focus groups/ setting sample sizes and in reporting ranges of estimates?
- Which sub-populations face different costs or access to goods and services and should thus be included in the purposive sample, for example rural vs. urban, gender, ethnicity, etc.?
- Which types of expenditures should be associated with disability?

The Goods and Services Required approach also requires additional questions:

- How to define the various levels of participating in society, for example survival and basic, equal or full socio-economic participation, and choose for which of these levels' estimates should be generated?
- How to best to reconcile differences in opinions on needs between the experts and focus groups?

The process of negotiating and agreeing upon these steps not only improves the methodology but generates understanding and ownership across stakeholder groups. This can help in efforts to use these results in making policy changes. These methods do not generate precise estimates but rather a range of costs and a picture of how expenditures are generally distributed across different goods and services. This is very useful for policy development but can be frustrating for someone coming from outside the process who is in search of a solid number that could be used, for example, as a universal top up for persons with disabilities receiving social protection benefits. Box 6 provides a case study for how the participatory nature of the GSR methodology aided in interpreting the results and having them affect policy.

Box 6: Participatory Approach to Estimation and Policy Development: Example from South Africa.

The GS/GSR approach taken in South Africa was designed as participatory research, to account for the diverse experiences of people with disabilities, and to build a consensus among stakeholders that could serve as the basis for policy reforms.^a The study was conceived, developed, and conducted jointly with the South African Department of Social Development (DSD), South African researchers and representatives from the disability sector, and received continued feedback and discussion of results with individual Disabled People's Organizations (DPOs).

This cooperation included formulating the goals of the study, determining the structure of the focus groups (including the types of disabilities to be considered), the recruitment of participants and validation of results. Recruitment targeted people with disabilities who were engaged in community outreach or held leadership positions within the representative DPOs and thus knowledgeable on disability related issues[1].

When it came time to debate potential policy responses, all stakeholders had ownership in the data collection process and were able to conduct those debates with a common, accepted understanding of the nature and extent of the extra costs associated with disability. This work then directly informed the White Paper on the Rights of Persons with Disabilities in South Africa, which now informs the development of all following policy and law reforms [4].

^aHanass-Hancock, J., S Nene, N Deghaye, S Pillay (2017), These are not luxuries, it is essential for access to life: Disability related out-of-pocket costs as a driver of economic vulnerability in South Africa, African Journal of Disability 6(0)

INCORPORATING DISABILITY EXTRA COSTS INTO THE DESIGN OF SOCIAL PROTECTION PROGRAMS AND SYSTEMS

Different countries have adopted diverse approaches to incorporating disability extra costs into the design of social protection programs and systems. 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.²¹ Benefits also often include adequate coverage of healthcare expenditures, such as through health insurance. 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 in a way that accounts for the diversity of costs faced by different groups of persons with disabilities. The two challenges are:

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

Integrating disability related cost in qualifying thresholds for means tested household targeted programs and adjusting program benefits

Adapting Means Test's Thresholds

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 some minimally acceptable level of wellbeing, 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 members with disabilities must cover 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 line or some fraction or multiple of it (that rate being based on requirements for a healthy diet,

²¹ Cote, A, (2021) Disability inclusion and social protection, Chapter 19 in Schuring, E. and Loewe, M. (eds.) Handbook on Social Protection Systems, Elgar, https://doi.org/10.4337/9781839109119

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 standard of living as persons without disability, persons with disabilities need to cover disability specific goods and services in addition to items such as 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 persons with disabilities who are effectively living below the poverty line will be excluded from those programs.

When it comes to accounting for the extra costs of disability in social protection programs there are several 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 threshold (Sol) Current Means test threshold disability costs (SOL) Current disability costs (SOL) Actual standard of Actual living standard of living В Α

Figure 6: Impact of Standard of Living Method measure on means test threshold

Figure 6 shows how not accounting for the extra expenditures being made by households with a member with disability undermines the effectiveness of a means test. The blue bars represent households without 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 standard of living as measured by the Standard of Living Method.

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 Standard of Living 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.

The same is true if benefit levels are set without regard to those extra costs. The extent to which those benefits lift persons with disabilities above the targeted standard of living will be lesser than for persons without disabilities. Therefore, in the absence of compatible disability allowance/benefits, it is essential that social protection programs incorporate the extra costs of disability into their design such as 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).

Under a Guaranteed Annual Income (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 households with persons with disabilities 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. ²² 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 it is argued that 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 with disability experienced extra costs equal to 50 percent of what a person without disability 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 Standard of Living Method.

This approach could basically be taken with respect to means-tested poverty alleviation programs by establishing separate programs for disability costs that are not means tested. That is, programs can be established to cover the extra costs of disability, through some combination of cash benefits, in-kind benefits, and concessions. Then, if people fall below the means test threshold

²² Carraro, L. and Castro Cumpa, M. (2014). Accounting for Different Needs when Identifying the Poor and Targeting Social Assistance. Paper Prepared for the IARIW 33rd General Conference Rotterdam, the Netherlands. August 24-30, 2014.

(excluding the value of the disability related benefits) they would qualify for poverty alleviation programs similarly to persons without disabilities. This approach, however, must go beyond looking at average costs, to covering the exact nature of those costs for different groups of people with disabilities (e.g., based on impairment type, severity, life stage).

It is important to note that this discussion only addresses the impact of direct costs. The discussion has been comparing households with the same income levels but different standards of living because of those extra costs. To fully measure the impact of disability on people's lives, however, it would also be important to incorporate the impact of foregone earnings. Many households with persons with disabilities will have lower levels of income, not even adjusting for extra costs, in part because they are providing in kind services to family members, such as personal assistance, instead of being employed. While this paper focuses on the issues associated with direct costs, that does not encompass the totality of the economic impact of disability on households.

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

The Standard of Living approach does not consider the diversity of goods and services required for participation but only compensate for part of the current economic impact of disability on households set as an average. 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 Standard of Living 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 functional difficulties as opposed to those with severe ones, or even people with large groups of impairments and old age. 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 will 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.

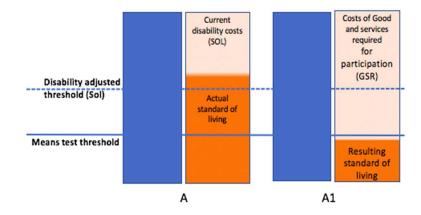
The size of extra costs depends on a variety of factors including not only the type and degree of disability but also the local environment and the current policy context. Another complicating factor is that the extra costs of disability can vary based on whether a person is working or not and to which extent their employer covers disability extra costs related to work. A study from Turkey, for example, shows that the extra costs facing persons with disabilities who were working were on 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, or maybe because those working were better able to afford required goods and services.

Many LMICs such as Nepal, Vietnam or Georgia among others have different levels of support for different levels of disability. This assumes that persons 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 shows that disability costs required for participation would on average be at least three times the poverty line for all persons with disabilities. The New Zealand study 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 7: Standard of Living Method vs. Goods and Services Required adjustments for extra costs



²³ Ipek (2019)

-

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 standard of living associated with this initial threshold as well as with the disability adjusted one based on the Standard of Living approach.

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 a severe disability living in a household belonging to even an upper decile may not be able to afford the support they require for equal basic participation without jeopardizing the household basic standard of living.

R50000 R45000 R40000

Figure 8: Income distribution in centiles Southern Africa Labor and Development Research unit, 2018 and GS cost estimates, DSD, 2015

R35000 Max cost for R30000 deaf person R25000 R20000 R15000 R10000 R5000 R0 20%

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. See the example of Brazil in Figure 9. In South Africa people had extra costs several times the level of poverty. If that were true in

Brazil, with a poverty line for an average sized household at 420 reals per month, those costs would dominate a large share if not all their income before paying for all other household expenses.

Box 7: Ongoing Efforts to Estimate Extra Costs of Disability

Recently several studies have been undertaken to estimate the extra expenditures associated with disability. For example, in Indonesia the Standard of Living Method and the GSR method was completed last year at the request of the Ministry of Finance as part of their process to reform disability benefits. In Georgia a study using the GSR method is nearly finished to estimate the extra costs of disability for children, the methodology of which is now being applied in Peru. Also, another study using the GSR method for adults in Kenya and Bangladesh is also nearly completed.

Need for Multiple Programs

One of the issues that is often missed by policy makers and advocates alike is that for most people with severe 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. ²⁴

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 – both at the individual level to cover existing costs and at the societal level to remove the barriers that can create high direct costs – like inaccessible infrastructure – and high indirect costs such as barriers to education.

²⁴ https://www.sciencedirect.com/science/article/abs/pii/S187506722030047X

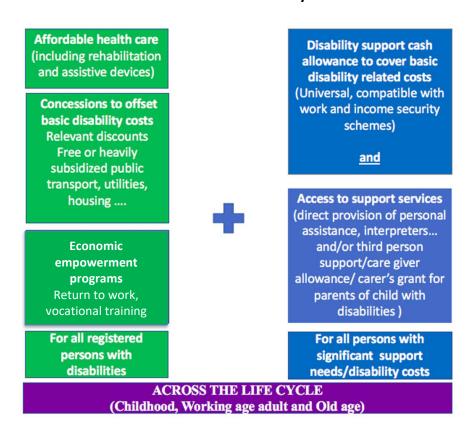


Figure 9: Combination of schemes to cover disability related costs

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 that caters to the needs of persons with disabilities 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. Progressively rolled out, this could be granted first to children with disabilities as well as working age adults and older persons with significant support needs. 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. If possible, such an allowance could also be broken down in 3-4 support needs groups each allocated a different amount of cash allowance.
- 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, or 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, United Kingdom...).
- 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.
- *Investment in public services:* including improving the accessibility of infrastructure, including transport systems, and investing in inclusive education and health systems.

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. Also, it must be kept in mind that even disability itself can be a fluid condition that people go in and out of over their lifetime.²⁵

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, adequacy of the benefit is very low. In Fiji, persons with severe 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.

Healthcare expenditures are a major source of extra costs. For example, in Indonesia onset of disability was associated with a 31% increase in health expenditures [5], while adults with moderate to severe disabilities in Vietnam spent 2-5 times more on healthcare compared to persons without disabilities [6]. Health expenditures can be highly variable based on the type and severity of an individual's impairment, as well as the quality, affordability and availability of needed health services in an individual's area. Consequently, cash transfers alone are unlikely to cover all needed health expenses, and complementary programs such as social health protection (e.g. health insurance, universal health coverage) should be explored. In Turkey, the implementation of universal health insurance was associated with a 34 percentage point decrease in total disability-related extra costs [7]. Similarly, reforms to existing programs, such as increasing the coverage of disability-related health services or subsidizing co-payments for persons with disabilities can reduce costs borne by individuals and their households [8, 9].

 $^{{}^{25}\}underline{https://www.researchgate.net/publication/261218954\ The\ risk\ of\ developing\ a\ work\ disability\ across\ the\ adu\ \underline{lthood_years}$

Excluding medical expenditures, most 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 3: 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 severe 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, this 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 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 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 pay 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

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 estimate direct costs.

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:

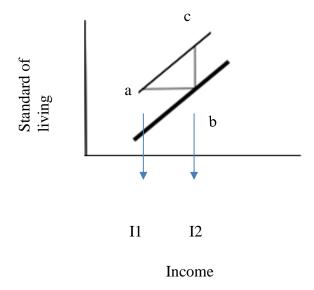
- 7. Social protection programs should account for the extra costs of disability. Clearly the extra costs of disability are significant and can stand in the way of equal participation for people with disabilities, push them in poverty or prevent their escape from it. This includes the extra costs associated with seeking and retaining work or accessing education. Policies should be constructed to remove those barriers.
- 8. There are different approaches to estimate disability related direct 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. It can also be used to identify different levels of disability support needs and help to develop social protection measures that account for the diversity and difference in disability related cost.

- b. The Good and Services (GS) and GSR methods should be used together for more detailed exploration of the impact of and ability to meet 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 Standard of Living 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 Standard of Living Method can be soundly pegged to GS/GSR estimates, and thus contribute to these purposes.
- 9. Disability adjusted means test thresholds and amounts 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.
- 10. 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 an affluence (wealth) test basis but not poverty (income/consumption) targeted.
- 11. 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 and accessible health care coverage.
- 12. 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.

ANNEX A - Technical Note on Standard of Living Method

This basic economic approach developed by Zaidi and Burchardt is shown graphically in the figure below. The higher line shows the relationship between income and standard of living for persons without disabilities and their families. As income increases, so does the standard of living. That rate of increase is the same for families with members with disabilities, but their line is lower because of the extra costs of disability, which in this model are assumed to be fixed. So, for a person without a disability to have a standard of living equal to "a" in the figure needs an income level of "I1", but a person with a disability needs a higher level of income, which is represented in point "I2" in the figure.

Figure A1: Standard of living, income, and disability, with fixed extra costs



Zaidi and Burchardt (2005) formulate the standard of living approach as

(1)
$$S = \alpha Y + \beta D + \gamma X + k$$

where S is an indicator of the standard of living, Y is household income, D is disability status, and X are other household characteristics. The constant k is an intercept term, which Zaidi and Burchardt interpret as representing the absolute minimum level of standard of living (under which the household could not survive).

The extra cost of disability, E, is given by

(2)
$$E = dY/dD = -\beta/\alpha$$

Using Figure A1, this can be seen graphically. The parameter β – the fixed impact of disability on standard of living -- is the distance CB between the lines and the parameter α is the slope of the line, which is CB/AB. Thus β/α is CB/(CB/AB) which equals AB which is the extra cost of disability.

The standard of living, S, needs a proxy of some sort. The most common measure of the standard of living in the literature is wealth, represented by an asset index, but other indices could be used. For example, studies have used standard of living indicators based on self-rated financial satisfaction,²⁶ ability to afford different desired goods and services²⁷, or subjective assessment of ability to make ends meet²⁸.

The main methodological issue with the Standard of Living approach is constructing the measure for the standard of living. This can be a subjective measure, such as "the difficulty to make ends meet" as has been used in studies in higher income countries²⁹, or a measure such as an asset index. For the latter, Filmer and Pritchett (2001) suggest principal components analysis (PCA) to combine a set of dummy asset variables into a single index in a way that provides more accurate weights than simply summing the number of assets held³⁰. The intuition is that there is some underlying latent variable that describes wealth that is reflected in the assets held by a family. PCA transforms a set of observations of possibly correlated variables (e.g., ownership of different assets) into a set of values of linearly uncorrelated variables called principal components. That way, when creating the index any correlation between ownership of various assets is weeded out. This is the approach taken in a recent study in Bangladesh looking at the correlation between

²⁶ Nghiem, S., et al., *Implicitly Estimating the Cost of Mental Illness in Australia: A Standard-of-Living Approach.* Applied Health Economics and Health Policy, 2020. **18**(2): p. 261-70, Vu, B., et al., *The costs of disability in Australia: a hybrid panel-data examination.* Health Economics Review, 2020. **10**(1): p. 6.

²⁷ Li, J., et al., *Inequalities in standards of living: evidence for improved income support for people with disability.* 2019, Solmi, F., M. Melnychuk, and S. Morris, *The cost of mental and physical health disability in childhood and adolescence to families in the UK: findings from a repeated cross-sectional survey using propensity score matching.* BMJ Open, 2018. **8**(2): p. e018729, Morciano, M., R. Hancock, and S. Pudney, *Disability Costs and Equivalence Scales in the Older Population in Great Britain.* Review of Income and Wealth, 2015. **61**(3): p. 494-514.

²⁸ Antón, J.I., F.J. Braña, and R. Muñoz de Bustillo, *An analysis of the cost of disability across Europe using the standard of living approach*. SERIEs, 2016. **7**(3): p. 281-306, Morris, Z.A. and A. Zaidi, *Estimating the extra costs of disability in European countries: Implications for poverty measurement and disability-related decommodification*. Journal of European Social Policy, 2020. **30**(3): p. 339-354.

²⁹ Morris, Z.A. and A. Zaidi (2020) *Estimating the extra costs of disability in European countries: Implications for poverty measurement and disability-related decommodification.* Journal of European Social Policy 30(3): p. 339-354.

³⁰ Filmer, D., & Pritchett, L. H. (2001). Estimating wealth effects without expenditure data—or tears: an application to educational enrollments in states of India. *Demography*, *38*(1), 115-132.

wealth and disability.³¹ A benefit of PCA is that the coefficient on each asset reflects how much information it provides about the other assets. So, for example, if owning a computer is indicative of being among the wealthy few, but many people own radios, then owning a computer will receive a higher weighting. And if owning a particular asset is more likely to be owned by poorer people (say a bicycle instead of a car) then it will have a negative coefficient. Thus, summing the principal components is a more accurate reflection then simply summing the number of assets.³²

As Moser and Felton point out, however, an even better approach is polychoric PCA which deals more appropriately with ordinal data. ³³ For example, HIES's often ask about the quality of construction of a home, which in Bangladesh could be kutcha, semi-pucca, or pucca. Polychoric PCA assigns each type of asset the value of a discrete variable and ensures that the coefficients of an ordinal variable follow the order of its values. It also allows the computation of both owning and not owning an asset.

As Moser and Felton explain:

If almost every household owns indoor plumbing except for the very poorest, then the coefficient on owning indoor plumbing will be around zero (since it does not help distinguish household wealth among those that own it). However, not owning indoor plumbing will be negatively correlated to ownership of other assets and the coefficient of not owning it will be highly negative. This further distinguishes among wealth levels.

³¹ Tareque I, S Begum, Y Saito (2014) Inequality in Disability in Bangladesh, PLOS ONE, July, Sen B, M Hoque, (2017), "Unpacking Disability Extreme Poverty Links in Bangladesh through Household Income and Expenditure Surveys: A Quantitative, Exercise. *Chronic Poverty Advisory Network*

³³ Moser, C., & Felton, A. (2009). The construction of an asset index. *Poverty dynamics: interdisciplinary perspectives*, 102-127.

REFERENCES

Antón, J.I., F.J. Braña, and R. Muñoz de Bustillo (2016) *An analysis of the cost of disability across Europe using the standard of living approach.* SERIES 7(3): p. 281-306

Asuman, D., Ackah, C.G. & Agyire-Tettey, F. (2021) Disability and Household Welfare in Ghana: Costs and Correlates. *J Fam Econ Iss* 42, 633–649 https://doi.org/10.1007/s10834-020-09741-5

Cote, A. (2021) Disability Inclusion and Social Protection, Chapter 19 Schuring, E. and Loewe, M. eds.) Handbook in Social Protection Systems, Elgar

Disability Resource Center. (2008). The Cost of Disability: Final Report. Report prepared for the Ministry of Social Development. New Zealand. February 2008.

Filmer, D., & Pritchett, L. H. (2001). Estimating wealth effects without expenditure data—or tears: an application to educational enrollments in states of India. *Demography, 38*(1), 115-132.

Groce, N., and Mont, D. (2017) "Counting disability: emerging consensus on the Washington Group questionnaire." *The Lancet Global Health* 5, no. 7: e649-e650.

Hanass-Hancock, J. and McKenzie, T.C. (2017). People with disabilities and incomerelated social protection measures in South Africa: Where is the gap? *African Journal of Disability* (Online), 6, 1-11.

Hanass-Hancock, J., Nene, S., Deghaye, N. and Pillay, S. (2017). 'These are not luxuries, it is essential for access to life': Disability related out-of-pocket costs as a driver of economic vulnerability in South Africa. *African Journal of Disability* (Online), 6, 1-10.

Hancock, R., Morciano, M. & Pudney, S. (2013). Nonparametric estimation of a compensating variation: the costs of disability. Institute for Social and Economic Research Working Paper 26. University of Sussex.

ILO. (2017). World Social Protection Report 2017–19: Universal social protection to achieve the Sustainable Development Goals; page 66-73 International Labour Office – Geneva.

Ipek, E. (2019). The costs of disability in Turkey. Journal of Family and Economic Issues, 1-9.

John, E., et al., Disability Price Tag 2019. (2019) Policy Report

Joint Statement: Towards Inclusive Social Protection for the Empowerment of Persons with Disabilities, (2019)

https://socialprotection.org/discover/legal_policy_frameworks/joint-statement-towards-inclusive-social-protection-

systems#:~:text=The%20joint%20statement%20reflects%20shared,participation%20of%20persons%20with%20disabilities.

- **Li, J., et al.** (2019) *Inequalities in standards of living: evidence for improved income support for people with disability*
- **Minh, H.V., et al.,** (2015) *Estimating the extra cost of living with disability in Vietnam.* Global Public Health 10: p. S70-S79.
- **Mitra, S., Palmer, M., Kim, H., Mont, D., Groce, N.** (2017). "Extra costs of living with a disability: A systematized review and agenda for research," Disability and Health Journal
- **Mont, D., and Cote, A. (2020)** "Considering Disability Related Extra Costs in Social Protection," Inclusive Social Protection for the Empowerment of Persons with Disabilities, Background Paper #2, UNPRPD
- **Morciano, M., R. Hancock, and S. Pudney,** (2015) *Disability Costs and Equivalence Scales in the Older Population in Great Britain.* Review of Income and Wealth, 2015. **61**(3): p. 494-514.
- **Mont, D., Goodman, N., Morris, Z. and Nassir, M**. (2022) "Implications for using the Standard of Living Method for Estimating the Extra Expenditures on Disabilities in Africa," (forthcoming)
- **Morris, Z.A. and A. Zaidi** (2020) *Estimating the extra costs of disability in European countries: Implications for poverty measurement and disability-related decommodification.* Journal of European Social Policy 30(3): p. 339-354.
- **Morris, Z.A., et al.** (2020) *The Extra Costs Associated with Living with a Disability in the United States. Journal of Disability Policy Studies*, 2020: p. 10442073211043521
- **Moser, C., & Felton, A.** (2009). The construction of an asset index. *Poverty dynamics: interdisciplinary perspectives*, 102-127.
- **Nghiem, S., et al.,** (2020) *Implicitly Estimating the Cost of Mental Illness in Australia: A Standard-of-Living Approach.* Applied Health Economics and Health Policy, 2020. **18**(2): p. 261-70
- **Palmer, M., J. Williams, and B. McPake**, (2019) *Standard of living and disability in Cambodia.* The Journal of Development Studies, 55(11): p. 2382-2402
- **Poirier, M.J.P., Grépin, K.A. & Grignon, M.** (2020) Approaches and Alternatives to the Wealth Index to Measure Socioeconomic Status Using Survey Data: A Critical Interpretive Synthesis. *Soc Indic Res* **148**, 1–46 (2020). https://doi.org/10.1007/s11205-019-02187-9
- **Saunders, P.** (2007). The Costs of Disability and the Incidence of Poverty. *Australian Journal of Social Issues, 42,* 461-480.
- **Sen B, M Hoque** (2017), "Unpacking Disability Extreme Poverty Links in Bangladesh through Household Income and Expenditure Surveys: A Quantitative, Exercise. *Chronic Poverty Advisory Network*

Solmi, F., M. Melnychuk, and S. Morris (2018) *The cost of mental and physical health disability in childhood and adolescence to families in the UK: findings from a repeated cross-sectional survey using propensity score matching.* BMJ Open. **8**(2): p. e018729

South African Department of Social Development – SADSD. (2016). Elements of the financial and economic costs of disability to households in South Africa, Results from a pilot study.

Tareque I, S Begum, Y Saito (2014) Inequality in Disability in Bangladesh, PLOS ONE, July,

Tibble, M. (2005). Review of existing research on the extra costs of disability, UK Department for Work and Pensions Working Paper No 21

Touchet, A. and M. Morciano, (2015) *The disability price tag: technical report.* 2018, SCOPE: London, UK

UNCESCO (United Nations Educational, Scientific and Cultural Organization). (2010). Education for all global monitoring report: Reaching the marginalized (Paris).

Vu, B., et al., (2020) *The costs of disability in Australia: a hybrid panel-data examination.* Health Economics Review **10**(1): p. 6.

WHO/World Bank (2011) World Disability Report

Zaidi, A., & Burchardt, T. (2005). Comparing Incomes when Needs Differ: Equivalization for the Extra Costs of Disability in the U.K. *Review of Income and Wealth, 51,* 89-114.