disabilities

Article

Methods for Estimating the Impact of Disability Costs for Designing Inclusive Policies

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Abstract: The impact of disability on people's lives is often underestimated because the extra costs of living with a disability are not accounted for. This paper analyzes several different methodologies for estimating those costs and explores their usefulness in designing inclusive social policies. For example, one approach is to measure what is currently being spent, while another is to estimate what would need to be spent for equal participation. These can be measured using statistical techniques or through a more qualitative methodology. Each of these methods has its advantages and disadvantages. The paper concludes with recommendations for which methodology fits which purpose, and how they can be used together to obtain a full accounting of the extra costs incurred by people with disabilities.

Keywords: disability costs; social protection; inclusion

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1. Introduction

Disability is highly associated with worse outcomes across many indicators [1]. Most studies on poverty show a significant correlation between income or consumption poverty measures and the existence of a member with a disability in the household [2,3]. However, disability is also associated with lower levels of achievement on other dimensions of poverty. Whether looking at education [4], employment [5], health [6], violence [7,8], living conditions, water and sanitation [9], and even a sense of autonomy [10], persons with disabilities fare worse than persons without disabilities. For that reason, many have argued that a multidimensional approach to looking at the relation between disability and poverty is more appropriate [11,12]. In fact, studies that have looked at both consumption and multidimensional measures of poverty in the same country have found higher rates of poverty for persons with disabilities with the latter approach [13,14].

Often neglected in the past, but for which attention is growing, is the potential effect of the extra costs that persons with disabilities and their families often incur. To achieve the same standard of living and participation, persons with disabilities need to spend more both on disability-specific items, such as wheelchairs and sign language interpretation, and on non-disability-specific items, such as medical care, transportation, education, and housing [15]. Not accounting for these extra costs underestimates the levels of poverty experienced by persons with disabilities and their household. For example, a household living above the poverty line with a member with a disability may effectively have less income available for basic necessities, such as shelter, food, or sanitation, compared to a household without a member with a disability. When those costs are included, the household in question may fall below the poverty line and, in any case, reach a lower living standard if the state does not fulfill its obligation to accommodate disability-related needs. If those additional expenditures are not made, persons with disabilities may face serious deprivations that undermine their quality of life and, in some cases, may even threaten their lives, thus contributing to their level of multidimensional poverty, reducing their standard of living and right to life.

The extent of deprivations and barriers that persons with disabilities face and the extra costs that they entail in trying to offset them, arise from a complicated process, which is described in the social model of disability [16]. People come into the world with many characteristics, including functional limitations linked to an impairment. Often, such an impairment requires facing specific health expenditures. Moreover, if the world in which they come into has barriers to participation, it excludes people from the opportunities and resources they need to exist in that world on an equal basis to others. The above include physical barriers, such as inaccessible infrastructure, information/communication barriers, such as a lack of Braille, text to voice and accessible websites, sign language interpretation, and accessible easy-to-read documentation, and attitudinal barriers fostering discrimination. Other factors limiting participation could also include the lack of policies or support systems that promote and enable inclusion and accessibility.

Removing these barriers and providing those kinds of support are expected to decrease the outcome gaps between persons with and without disabilities, as well as the extra costs of living that person with disabilities face. However, the removal of these barriers would most likely not eliminate those extra costs altogether. Even with inclusive programs and policies in sectors such as education, health, transport, employment, and disaster risk management, among others, families of persons with disabilities will most likely face extra costs associated with said disability. Therefore, to ensure equal rights for persons with disabilities, governments will have to consider policies that address those costs. Doing so requires a methodology for assessing the nature and extent of the extra expenditures required by families with members with disabilities. This paper considers various measures of estimating those costs and discusses how they could inform social protection policy.

2. Approaches to Measuring Disability Costs: Methods and Discussion

Two basic approaches exist towards measuring disability costs. The first is to measure what expenditures directly related to disability are currently being spent by households. The second is to measure what would be needed to guarantee the equal participation in society of a person with a disability.

The first approach (i.e., measuring the amount currently being spent) tells us the current impact that paying for disability-related needs has, at a household level, on the consumption of non-disability-related goods and services. Subtracting the current expenditures from a household's consumption, thus, tells us what is available for other necessities and can thus identify households that are effectively living below the poverty line even if their overall level of consumption exceeds that line. The following three methods exist for estimating extra expenditures: (1) the Goods and Services Used (GS) method, (2) the Standard of Living (SOL) method, and (3) a general examination of the patterns of expenditure, all three of which are further explained below.

However, measuring the current levels of expenditure may not be sufficient to allow for the full participation of persons with disabilities if households are not able to afford, access, or know about the goods and services they need. The method which determines that level of expenditure is known as the Goods and Services Required (GSR) approach, which is also explained below. As such, the GSR approach is well-suited for providing a roadmap on how promote full participation.

A gap might exist between what is currently being spent and what is required for equal participation due to several reasons. First, a household may have insufficient income to purchase what is needed. Second, a specific good or service might be difficult to acquire or may not be available in a specific context. Third, a household may lack knowledge about the goods and services needed. Finally, intra-household inequalities, discrimination, and priority settings may be present, which would restrict the allocation of resources towards the inclusion of the person(s) with disabilities in the household. The two approaches to measuring disability costs are shown in Table 1.

Table 1. Basic approaches to measuring disability costs.

	Data Collected	Purpose
Current expenditures	Current expenditures on disability-related items and extra expenditures on general items that result from disability	To assess the current economic impact on households with members with disabilities
Expenditures needed for full participation	The types and amounts of expenditure on the goods and services that are required for equal participation in the current environment	To help develop policies and programs that can promote equal participation

The methods discussed below take different approaches and, thus, have relative advantages and limitations. They can be used for different purposes or in conjunction with one another.

2.1. Goods and Services Used (GS) Method

The GS method directly asks persons with disabilities or their household members which current spending of theirs is linked to their disability. This information tells us not only what is being spent but also what particular goods and services it is being spent on. This latter part is important because the nature behind what is being spent can differ quite dramatically according to the type and severity of a disability and the level of support needs [17].

A drawback of this approach is that the range and nature of purchases can be quite broad, so it requires an extensive survey or a detailed qualitative interview [18]. At times, people may not even be aware of all the extra expenditures they are covering until they are asked to focus on them. For example, they may be living in a city or neighborhood because it is near where the needed disability services are available, requiring higher rents than they may otherwise need to pay. They may require buying pre-chopped vegetables because of their difficulties with manual dexterity. They may also require more frequent health visits that are difficult to disentangle from average health care costs. A survey to fully capture the extent and nuances of this spending is difficult and long, increasing measurement error and the risk of lower response rates. In addition, it may be difficult to obtain an adequate sample size for making reliable estimates, particularly by type and degree of disability. An adequate sample size is required also for assessing how disability-related expenditures change when people have different levels of income. Furthermore, focusing exclusively on a survey of persons with disabilities risks complicating a rigorous comparison with the level of expenditure of other people: persons with disabilities cannot estimate the 'counterfactual' or the expenditure that they would have incurred had they not had a disability.

2.2. Patterns of Expenditures

Another approach that looks at current expenditures and the type of expenditures being made involves the use of consumption data collected through surveys with detailed information on expenditures such as HIES data in order to see how the current spending is allocated over various spending categories. The HIES typically collect data on consumption or expenditures, including what is spent on food, housing, health, education, and other items. Studies that have taken this approach have found, not surprisingly, that households with disabilities spend disproportionately more on health care and transportation compared to households without a member with disabilities. Also, these households spend less on education and other items, including food [19–21].

The pattern of expenditures approach is useful because it can highlight specific areas of spending (e.g., health and transportation) where especially high expenditures are being made by households with disabled members. This can help in designing efforts to reduce or subsidize those costs. It can also show the tradeoffs that households with disabled members may face. For example, one study in Vietnam found that, while the overall consumption did not change with the onset of a disability, the pattern of spending changed—more on health care, less on education, and the taking out of more loans [22].

Of course, as with SOL, the use of HIES for this purpose requires the inclusion of questions identifying persons with disabilities.

This method does have limitations. First, this method only analyzes differences in consumption patterns but, in itself, does not quantify the 'cost of disability' or the extra expenditures being made due to a disability. Furthermore, different patterns of consumption must be assessed in relation to the income levels of households with and without persons with disabilities. Second, HIES surveys typically do not ask about disability-specific items, such as assistive technology or personal assistance, nor do they directly address which portion, if any, of household expenditures on general items are linked to disability. Third, they do not always say on whom money is being spent within the household and, thus, ignore potential intra-household inequalities related to disability. Finally, considering patterns of expenditures does not mention the goods and services required by persons with disabilities to participate in society or achieve wellbeing that were not purchased because they could not access them for various reasons.

2.3. Standard of Living (SOL) Method

The SOL method was originally developed by Berthoud et al. (1993) and further improved and disseminated by Zaidi and Burchardt to estimate the average extra expenditures needed by a household with a person with a disability to have the same standard of living as a similar household without such a person [23,24]. The assumption behind this method is that two households with the same level of income and similar characteristics (e.g., place of residence, household size, etc.), but one with a member with a disability and one without, would have the same standard of living if it were not for the extra expenditures associated with the disability that they are currently making.

The SOL method involves estimating a regression with a standard of living measurement as the dependent variable and income or consumption, the presence of a person with a disability, and other household-level characteristics as the explanatory variables. Using the coefficients of that regression, Zaidi and Burchardt estimated the level of extra expenditures a household with a person with a disability needs to achieve the same standard of living as a household without a member with disabilities.

A key issue in SOL is what measure of standard of living to use. Zaidi and Burchardt maintain that a good SOL measure should be highly elastic with income and based on goods and services that are universally valued and not of a higher preference among persons with disabilities. Care should be taken to use a measure that can capture variation of expenditures across low-income and high-income households and be a composite measure that can average-out variations in taste.

Different SOL measures can lead to different results, even when using the same data sources. For example, SOL estimates of extra costs were generated for thirty-one countries in Europe using two different measures of standard of living, one based on a principal component analysis of assets and household characteristics and the other based on the level of difficulty in being able to make ends meet. Across the thirty-one countries, the estimates of extra costs as a proportion of household income varied from four to seventy-three percentage points [25].

One SOL measure often used is an asset index or wealth index. An asset index is constructed using principal component analysis starting from a set of assets (e.g., durable goods, living condition measures such as type of sanitation, materials of walls, roofs, floors, etc.) and, as such, is a measure of wealth. Thus, the SOL estimates based on this index can tell us how much extra income is needed for households with disabilities to achieve the same level of wealth as similar households without a disability. However, there are some limitations in comparing wealth that is accumulated over time—for example, those assets could have been accumulated before the onset of a disability. Also, difficulties arise when comparing assets in complex and large household structures where the assets and wealth may only be marginally related to disability. In general, when a person with disabilities lives in a large household, the estimation of the extra cost of said disability is likely to be more difficult to measure. One approach taken is to divide the extra cost estimates by the proportion of household members with a disability, which allows for the differences in extra costs per person that may occur if there is more than one person with a disability in the household.

Also, it is important to remember that the estimate arising from this method correlates to the average extra expenditures being made in the current environment. As such, the measured "costs" will vary according to the average income level in the country (people living in poverty do not have the necessary money to spend) and the availability of markets for disability-related goods and services, as well as the households' composition/types. For that reason, SOL estimates have tended to be much higher in high-income countries than in low-income countries [26].

Moreover, this measure of wealth does not capture the deprivations that persons with disabilities can face even with a certain level of income. For example, more income does not allow a child with a disability to attend a school that is inaccessible or will not accept them.

For this reason, another measure to consider is one that captures multidimensional poverty [27]. This approach focuses on the outcomes that are produced with the available resources. The goal is to measure how much extra expenditure is needed to obtain the same level of wellbeing, such as those related to health, education, employment, living conditions, etc.

Unfortunately, multidimensional poverty indices (MPI) pose significant data challenges, especially when these questions are added to an already-complex survey capturing income and consumption expenditure. Documenting deprivations at the individual level has significant data requirements; although some indicators, such as school attendance and work participation, are widely available, information regarding accessibility and how inclusive services are is generally lacking. Also, there is the challenge of knowing which deprivations to use and how to weigh them, as the results may be very sensitive to how the MPI is constructed.

More fundamentally, there is the issue of how one conceptualizes the estimate for the extra level of expenditures needed to obtain an outcome that cannot be obtained in the current environment. For example, if there are few inclusive schools or there is a discriminatory education policy, then additional household-earned income or social protection cash transfer will have little impact on reducing the education-related deprivation of a child with a disability and reduce the MPI's disability gap. Therefore, SOL will yield an estimate, but it is not clear how this could be used to inform policies, especially with respect to cash transfers for persons with disabilities. In this context, it is important to highlight that cash transfers should be complemented by more inclusive policies to be able to guarantee the inclusion of persons with disabilities. This is the conclusion reached in a recent study on the cost of disability in the Philippines, where the SOL measure uses both multidimensional deprivation indicators and the asset index [14].

Another type of SOL measure that is used is a subjective measure. For example, respondents answering a question asking them to rate on a scale their ability to make ends meet [28,29].

The results of the SOL method can be sensitive to people's subjective scales of well-being, which can be dependent on their current characteristics but also their personal histories. Financial security, for example, is relative. Two people in the same situation may feel differently because of the level of risk they are used to and can tolerate. And, as with the MPI approach, it is challenging to conceptualize how cash transfers designed to offset disability costs can be converted into the desired outcome of increased subjective wellbeing.

After choosing an SOL measure, the next step is choosing the control variables. In addition to income and the presence of a household member with a disability, other factors to consider are the household size, whether a household lives in an urban or rural area, the region of residence, and the age, sex, and education of the head of household. Another thing to account for is whether there could be "economies of scale" when it comes to disability costs if there is more than one person with a disability in the household, which leads to a slightly different specification. Instead of the presence of a person with a disability in the household, the variable used could be the number of people in the household with a disability [25].

Generally speaking, a typical Household Income and Expenditure Survey (HIES) has all the variables needed to produce an SOL estimate, provided that it contains questions identifying whether a household member has a disability. These surveys are widely collected and available in many countries, with a growing number containing internationally comparable disability questions as developed through the Washington Group on Disability Statistics.

In the end, the SOL tells us, in the current country-context with the currently existing barriers, policies and supports, and availability of the goods and services needed, how much more is needed to have the same standard of living of a household without a member with disabilities, as measured through the SOL measure being used. Therefore, the SOL must be used with caution when comparing disability costs across different countries, especially for those which have very different contexts.

Moreover, even within a country, not all people are living within the same context. For example, it could be that people in the highest income quintiles have the access and ability to purchase what they need, whereas those in the lowest income quintile may not. Therefore, if the sample size permits, SOL estimates could be made according to income quintile.

The functional form used to assess the relationship between income/consumption expenditure and SOL is important also to assess how the absolute disability cost changes at different levels of income. Most often, income/consumption expenditure is analyzed in a logarithmic form, which, in combination with a dummy variable for disability, implies a constant proportional cost, i.e., an increasing absolute disability cost, as we move from low to high income levels. However, a proper assessment of how the extra cost changes with income needs sufficient data. Also, disability costs can vary according to the type and degree of a disability, but, generally, the household surveys used in an SOL estimation are not large enough to estimate those costs for those subpopulations.

Care must also be taken when comparing estimates within a country over time. For example, it may be difficult to know if rising disability expenditures are good (e.g., people have more money and a higher availability of goods and services, so they are spending more) or bad (e.g., barriers are increasing or the relative cost of disability-related goods is increasing). Furthermore, the mix of assets that people own can change over time for reasons unrelated to disability, so the the asset index may not be consistent. The PCA does not allow for comparisons over time because the way in which each variable contributes to the first component depends on the sample. In addition, sometimes the questions on household surveys change over time, and it is not clear how that would affect the results, and the survey error in who is identified year-to-year could have an impact on the SOL estimates.

The SOL gives us an insight into the average reduction in the standard of living of a household with members with disabilities in a specific context, and it provides information on how those averages may be different across regions, income quintiles, or other large population groups. However, it does not provide much guidance on the design of social protection policies aiming to increase the wellbeing of persons with disabilities, as it does not tell us which goods and services are being purchased and what barriers to resources and participation persons with disabilities face. Nevertheless, if the survey used in an analysis contains information on key deprivations, different SOL measures and estimates of extra costs can be complementary and identify the scope of different policies.

2.4. Goods and Services Required (GSR)

As stated earlier, the GSR approach attempts to estimate what is needed for equal participation. Participation in the social model's context means ensuring that individuals with disabilities have equal access to opportunities, services, and resources and are actively engaged and included in society. It does not mean the fulfillment of all wants, but rather the ability to assume social roles on an equal basis to others.

The GSR method takes a qualitative approach, relying on a team of experts representing the diversity of persons with disabilities, parents of children with disabilities, rehabilitation professionals, and other service providers, who, with input from a series of focus groups of people with different types of disabilities and support needs, decide upon what goods and services are required and, then, price them.

The data collected from the expert and focus groups are organized according to the type of expenditures required, i.e., human assistance, assistive devices, home adaptations, etc., for participation in education, employment, transportation, leisure, and community living and for participation in decision-making processes [17,18].

These studies show a large variance among persons with disabilities in the amount of expenditure needed, as well as a significant variance in what goods and services are required. It can identify major cost-drivers and be used to create case studies to demonstrate how the costs of participation are incurred.

This method, too, has its limitations. First, it provides costs in the current context, with existing barriers, as well as the limited availability and high prices of some goods and services, prices which could be reduced with an economy of scale and subsidies, e.g., assistive devices. Therefore, it does not give guidance on how those costs can be best addressed by reducing environmental barriers, as opposed to providing cash, goods, or services to overcome those barriers. A GSR estimate does not immediately imply that all the currently required goods and services need to be provided on an individual level.

For example, the higher cost of transportation for persons with disabilities in a major city can be reduced significantly thanks to greater availability and accessibility of public transport vehicles and infrastructure overtime, combined with free public transportation concessions and a disability allowance for persons with disabilities.

And, of course, there is no hard scientific basis for determining what is "needed". This must be negotiated among the various experts and stakeholders involved in the process. While the support needs for realizing basic activities for daily living tend to be similar in different contexts, the support needed to reach equal participation can vary a lot in different contexts, both within and between countries. It is important to note that GSR estimates are not meant to be precise to the extent that they can be used to generate averages for the population, but are rather meant to show the range of potential costs, their structure, and the degree to which they can vary according to the type of disability and the level of support needed.

Moreover, among more marginalized groups (low income and/or living in remote areas), awareness about the different goods and services that could support greater functioning and participation can be limited, as well as their availability, which might affect the estimates. This will also be affected by people's preferences and cultural expectations, for example, with regard to how personal assistance is envisioned within a family's context. Further, not all types of required goods and services will be possible to cover at an individual level. For example, the cost of private transportation can be estimated when there are limited accessible public transportation options. However, the cost of other public services, such as inclusive education, may not be reflected in the GSR estimates, as it is beyond an individual's ability to pay for these services if they do not currently exist in their setting. All of this makes cross-country comparisons difficult but can still provide insight into the structure, variance, and extent of what are considered essential costs within a country. It may be possible to design other activities to complement the evaluation of costs, such as to elicit the willingness to pay via the type of games used in the study of behavioral economics. Surveying persons with disabilities on their self-reported out-of-pocket costs and unmet needs could also add important information to the GSR. Such surveys can provide information directly from persons with disabilities on their costs and needs, but will also encounter knowledge issues and be resource intensive and challenging to design for international comparability.

Still, what the GSR shows is useful for identifying specific needs, the diversity of those needs, and the major cost-drivers. In that regard, it is probably the most appropriate method for conceptualizing how to design policies to address them, whether they are focusing on the high costs resulting from environmental barriers (e.g., transportation) or on providing benefits at the individual level.

For example, a GSR study on children with disabilities in Georgia revealed that two major cost-drivers were personal assistance and assistive technology but that not all children needed them. Some children needed both, but some children needed neither. Thus, rather than providing cash to cover all possible expenses, programs could be developed to provide either subsidies or the direct provision of these goods and services. In the case of personal assistance, another way of reducing those costs could be to develop systems of community support. Greater inclusion in schools could also significantly reduce the childcare needed at home. Once these needs are covered, the residual extra costs would be much reduced and would vary much less across children with different types of disabilities, making those remaining costs more amenable to being covered by cash benefits. In most cases, the structures of the goods and services required are most likely best served using a suite of programs.

Similarly, the South African study on the elements of the financial and economic cost of disabilities revealed that there is a diverse difference in costs between persons with different types and degree of disabilities. The study revealed that transport, caregiver and learning assistance, communication devices, and maintenance of assistive devices emerged as the major drivers of out-of-pocket costs for persons with disabilities. It also revealed that the provision of learning and communication support, accessible transport, and appropriate assistive devices has a great potential to reduce the costs that households with persons with disabilities are currently carrying.

3. Conclusions

Persons with disabilities face significant costs to participate in society. Those costs are associated with a wide range of worse social and economic outcomes. The methods described here all provide useful information about the extent and nature of those costs and their impact on people's lives, but have limitations as well, which must be considered.

The SOL shows the potential reduction in welfare due to what is currently being spent. The GS and pattern of expenditures approaches provide information on where those expenses are being incurred, highlighting, for example, catastrophic health expenditures, and, combined with data on specific deprivations, can point to a lack of services. By focusing on patterns of expenditure, we can infer the impact of disability on how families' consumption choices are affected. The GSR provides a road map of where to focus efforts to ameliorate the reduction and/or coverage of those costs in a way that promotes equal participation and, so, can give specific guidance on the design of social protection policies.

These conclusions are summarized in the Table 2, below.

Table 2. Characteristics of different approaches to measuring disability costs.

Methods	Data Source	Use	Limitations
Standard of Living (SOL)	Household Surveys	Estimates the extra expenditures needed for an equal standard of living	Does not address what is needed for full participation. Does not provide details of how money is spent or what is needed for full participation.
Patterns of Expenditure	Household Surveys	Estimates the extra expenditures currently being undertaken	Does not provide what is needed for full participation. Surveys generally do not provide details on disability-specific items.
Goods and Services Used (GS)	Surveys and/or Focus Groups	Estimates the extra expenditures currently being undertaken, including disability-specific items	If focus groups are used, then it cannot provide population estimates. Surveys must be very extensive.
Goods and Services Required (GSR)	Focus Groups and Expert Groups	Estimates what is needed, i.e., what goods and services are needed for full participation	Does not show the current use of goods and services or the economic impact of current expenditures.

This paper makes the following recommendations:

- When examining the impact of disability on people's lives and when designing policies to offset those impacts, it is important to account for the extra costs associated with disability.
- The method used for examining those extra costs should align with its purpose. For example, analysts should consider whether the aim is to assess the current impact of those expenditures on people's lives or to determine how social protection programs should be designed.
- A combination of methods should be used to obtain a full understanding of how disability costs are currently being incurred, what their impact is on families, and how they could best be addressed.

Together, these studies can help identify and address the needs of persons with disabilities for policymakers, in their efforts to develop a more inclusive society.

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