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Extra costs of living with a disability: A review and agenda for research

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ABSTRACT

Background: There has been a growing interest in disability and poverty on the international research and policy stages. Poverty assessments for persons with disabilities may be affected by the experience of extra costs associated with a disability.

Objective: This article provides a systematized review of the global literature on the direct costs associated with living with a disability at the individual or household level.

Methods: We searched three databases for peer-reviewed journal articles that estimated extra costs associated with disability: Econlit, Socindex and PubMed.

Results: We found 20 such studies conducted in 10 countries. These studies were predominantly from high-income countries. Although studies were heterogeneous (e.g., in terms of disability measures and cost methodologies), estimated costs were sizeable and some patterns were consistent across studies. Costs varied according to the severity of disability, life cycle and household composition. Highest costs were observed among persons with severe disabilities, and among persons with disabilities living alone or in small sized households.

Conclusions: More quantitative evidence is needed using rigorous methods, for instance evidence based on longitudinal data and as part of policy evaluations. More internationally comparable data on disability is required for the quantitative evidence to develop, especially in low- and middle-income countries where studies are scarce. Qualitative and participatory research is also needed, especially to investigate unmet needs, and the consequences of extra costs.

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Introduction

There has been growing attention to disability and its complex links to wellbeing and poverty.¹ This phenomenon is underscored by references to disability in various parts of the Sustainable Development Goals, including on inequality. Worldwide, persons with disabilities experience worse education and labour market outcomes and are more likely to be poor than persons without disabilities.¹ This is true despite the fact that the United Nations

Convention on the Rights of Persons with Disabilities requires ratifying countries to guarantee the right to an adequate standard of living and social protection for persons with disabilities.²

This review focuses on the direct costs incurred by households or individuals living with a disability, which represent an important aspect of economic wellbeing. To achieve a reasonable standard of living, individuals who live in households with persons with disabilities must outlay additional resources relative to the population without disability. The presence of a household member with disability thus has important implications for poverty. Direct costs associated with disability are wide-ranging including additional out of pocket costs required for health services, medication, help with daily activities, disability-specific aid, etc. Direct costs are distinct from indirect costs, which include foregone economic

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activities (e.g. work) associated with the individual with disability and their primary carer/s in the household.

There exist a variety of methodological approaches to quantifying the direct costs of disability, which have been summarized (to differing degrees) in several reviews.^{3–5} Existing reviews of the literature, however, do not capture the recent growth of studies that apply a method of estimation known as the Standard of Living approach.^{4,6} This review of the literature aims to provide the first global review of studies on disability costs that use a variety of methodological approaches. Notably, the review presents recent findings from low- and middle-income countries (LMIC) as well as from high-income countries as distinct from previous reviews, which were limited to high-income countries.

Disability may lead to extra costs for individuals and households with disabilities. These expenditures may relate to general items that any household may need (e.g., health care, food) as well as to disability-specific items (e.g., assistive devices, rehabilitation, personal assistance, and house adaptation). Costs are influenced by the individual experience of the person: her impairment, resources, interaction with the environment she lives in, including the prices and accessibility of goods and services. Understanding influences on these costs is particularly important in an international context where environmental and policy contexts vary substantially. Differences in extra costs across countries may result from differences in government policies and programs. For instance, if country A subsidizes personal assistance but country B does not, that subsidy will decrease the relative costs of disability in country A for the household. This review paper focuses on private costs; if a service or commodity is covered, at least in part, by a transfer (e.g. payment through a public program), then the private cost is the cost born by the individual or household with a disability and is net of transfer.

One study⁵ categorizes the estimation of extra costs of disability into three conceptually distinct approaches. First, the *goods and services used* approach directly measures expenditures for persons with disabilities and compares them against persons without disabilities with the differential implied as the costs of disability. Such studies capture actual spending, however this may not provide a full picture of additional disability costs because the increase in spending will vary depending on the availability and financial accessibility of such services. This is especially important for developing countries, where low estimated expenditures may not be indicative of the impact of disability as much as it reflects the unavailability of needed goods and services. Forgoing needed goods and services may further bar people with disabilities and other members of their households from participating more fully in productive, domestic and community life, but such opportunity costs of lost productivity are outside the scope of this review and should also be considered when attempting to assess the full costs of disability.

A second methodology measures the *goods and services required* focusing on the extra costs of goods and services required by individuals with disability in order to perform particular activities that individuals are not currently performing due to their disabilities. In other words, it requires people to subjectively estimate extra costs of performing particular activities that they completely or partially cannot do. One key limitation is if people with disabilities are unaware of particular goods or services that could increase their participation in society, then these will not be accounted for. Once again, this will affect the relative estimated costs of disability between people in rich and poor countries, or even between people with different levels of education within a country.

A third methodology, the *expenditure equivalence* approach, is based upon the question of how much extra money a person with a disability would need to spend on all activities to achieve the same

level of wellbeing he or she could achieve with no disability.^{4,6} This is often referred to as the Standard Of Living (SOL) approach. The SOL approach does not require any expenditure measurement. It is an indirect method that is designed to identify the changes in the relationship between income and utility, here referred to as SOL. SOL can be measured in different ways, such as asset ownership, and is assumed to be positively related to income. The premise underlying the method is that households with disabilities are considered as having a different conversion from income into SOL due to the extra costs of disability. Extra disability costs are imputed as the additional income required to maintain the same standard of living as an equivalent non-disabled household, controlling for other sources of variation via regression. Costs are estimated overall and can be applied to account for variations in the level of costs across confounding factors such as the severity, life cycle, and household composition of disability.

Methods

We conducted a systematized literature review: systematized reviews include some but not all elements of a systematic review.⁷ Searches were conducted in three social science and public health databases: Econlit, SocIndex and PubMed. Relevant articles were searched using combinations of disability- and cost-related keywords. Disability-related keywords were as follows: disability, functional limitation, activity limitation, impairment, handicap, cripple, paralysis, injury. Cost-related keywords include: costs, extra costs, expenditures, and extra expenditures; healthcare services, medication, out-of-pocket spending, transportation costs and aid for daily activities. We considered not only general expenditures that people spend regardless of disability (e.g. health care) but also disability-targeted expenditures that only people with disability spend to maintain their health and daily lives. Fig. 1 presents different steps of the search and selection process in a flow diagram. Our search through the three databases yielded 11,316 articles. These were reviewed based on the title by one researcher. If the study was included based on the title, the abstract was then reviewed by two researchers. If the study was included based on the abstract, the full text of the article was read by two researchers and checked against the inclusion criteria below. The search led to 20 articles in total.

Inclusion criteria were as follows.

1. We included studies that estimated direct extra costs of disability at the household level or at the individual level, not at the national level.
2. The search was limited to peer-reviewed academic journal articles published from 1995 to 2014. We did encounter several relevant books,^{8,9} book chapters^{10,11} and reports,¹² but this review concentrated on relevant articles in peer-reviewed journals.
3. Included studies were those with detailed information about estimated direct extra costs of disability and methodology.
4. There was no limit on types of methodology; both qualitative and quantitative studies were included.

Results

Overview of the studies

In total, 20 papers are reviewed. Details on each study are in Table 1 including the country, age group, disability measure, data, sample size and reference level and research design (conceptual approach and methodology).

The group of countries under study is strikingly small, with only ten countries represented. Five papers focus on the extra costs of disability in the United States; four in the United Kingdom; three in Vietnam; two in Ireland and New Zealand; and one paper each in Australia, Canada, Spain, China and Bosnia. Overall, studies on extra costs of disability are largely focused on high income countries, with the exception of three LMIC countries: Bosnia, Vietnam and China.

Regarding the age groups under study, while only three papers assess the extra costs of disability for all ages, most papers in fact focus on specific age groups. Three papers estimate the extra costs for children with disability under 18; five papers focus on people aged 16 and above; six papers assess the extra costs for people aged 50 or 65 and above; and three studies estimate the extra disability costs for households whose heads are of working age.

The approaches to measuring disability differed across studies and can broadly be separated into (1) measures of functional and/or activity limitation (twelve papers), and (2) impairment based measures (eight papers). Ten papers presented costs for any severity level and ten papers by severity level. Severity classifications also differed. For instance, three studies^{13–15} measure the extra costs of disability for mildly/moderately and severely disabled individuals. Another study¹⁶ categorizes individuals based on deciles of disablement from the least severe category (level 1) to the most severe category (level 10).

Regarding the unit of analysis, ten papers use data at the household level and ten papers use data at an individual level. For papers at the individual level, among those that adopt regression estimation techniques (including the SOL approach) household composition is controlled for as an independent variable, typically

as household size or some equivalisation thereof. Among papers at the household level, households with disabilities are defined as households with at least one disabled member. Results were presented in different ways. For instance, some papers present results for all households^{17,18} whereas others further disaggregate into couple households and single person households.^{4,19}

With respect to the conceptual approach, eight out of the twenty studies measured extra costs that people with disability used. Nine studies estimated the equivalent level of expenditures for disabled people to maintain the same standard of living as people with no disability. Three studies^{20–22} measure both the extra costs used and required approaches.

On methodology, eight papers measure extra costs of disability using the SOL approach. Six papers use a descriptive analysis, i.e. they present means, and sometimes medians for persons with disabilities, sometimes compared to those of persons without disabilities. Another five papers use multivariate regressions analysis, sometimes combined with a descriptive analysis. Two papers use mixed methods based on both qualitative and survey data.^{21,22}

We present the results in turn for descriptive analysis and mixed methods (Table 2), multivariate regression analysis (Table 3), and for the standard of living approach (Table 4). In all tables, money amounts are given after being converted in 2010 purchasing power parity (PPP)²³ US dollars. In order to compare estimated values measured in local currency units in different years, PPP conversion factors and consumer price index from the World Bank are used for each country.

Eleven papers estimated overall disability costs whereas the remaining nine papers estimate specific costs including medical and non-medical costs. Medical costs include out-of-pocket

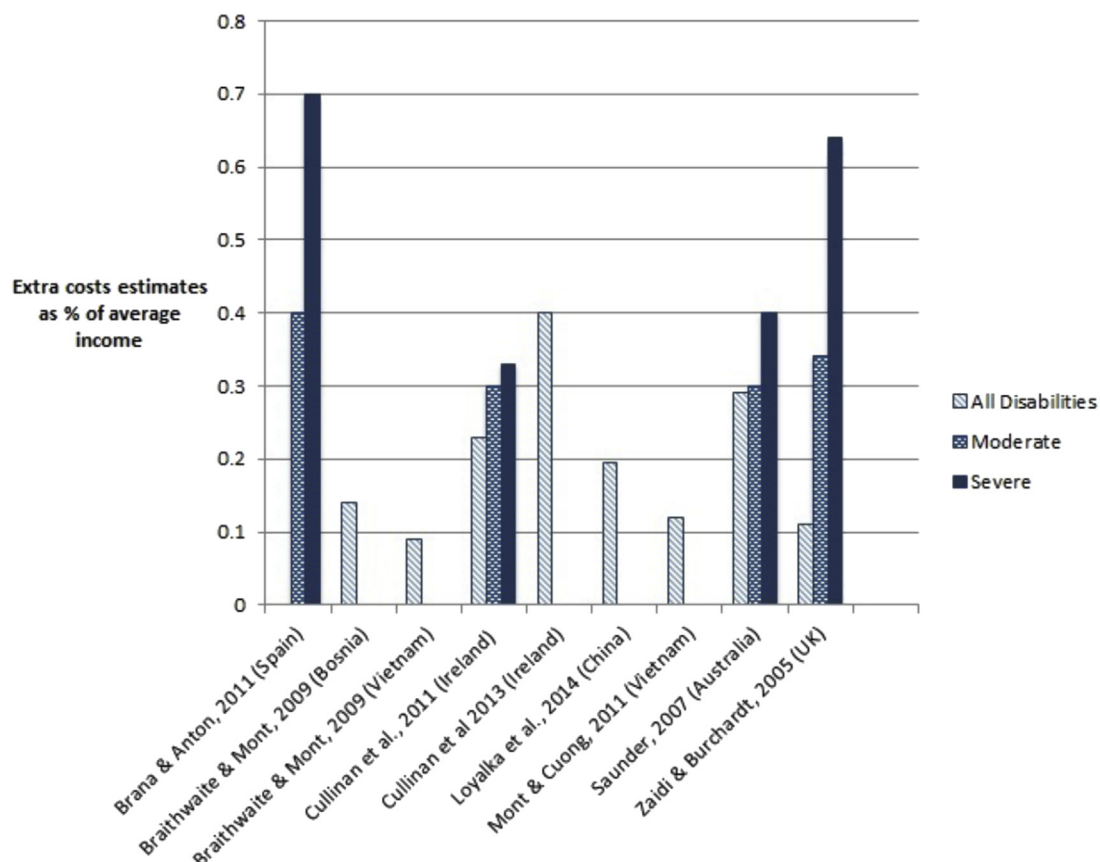


Fig. 1. Extra costs estimates using the Standard Of Living approach.

Table 1
Selected studies on extra costs of disability.

Reference	Country	Age groups	Disability measure	Data	Sample size	Conceptual approach	Methodology	Type of costs
Brana, J-P., & Anton, J-I. (2011)	Spain	Adults aged 17 and older	Chronic impairment or illness and with activity limitation in the past six months (moderate or severe)*	2007 Encuestas de Condiciones de Vida	12,191 households	Expenditure equivalence	Standard of living approach	All costs
Braithwaite, J., & Mont, D. (2009)	Vietnam Bosnia	People aged 5 and older	Presence of functional and basic activity limitations (sight, hearing, walking, cognition, communication, and self-care).	Vietnam and Bosnia Household Living Standards Surveys	3,971 for Vietnam, 16,965 for Bosnia	Expenditure equivalence	Standard of Living approach	All costs
Burton, P., & Phipps, S. (2009)	Canada	Parents/guardians whose children under the age of 5–14	1/Having difficulties hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities; or2/physical or mental condition or health problem reduces the amount or the kind of activity this person can do: At home, at work or at school, in other activities, for example, transportation or leisure	2001 Statistics Canada Participation and Activity Limitation Survey, Child Sample	4,561 individuals	Goods and services used, Goods and services required	Descriptive analysis and multivariate analysis among families with children with disabilities using probit model	Costs related to health care
Cullinan, J., Gannon, B., & Lyon, S. (2011)	Ireland	All ages	Presence of a disability or long term health condition (yes or no) and if yes, presence of a limitation in daily activities (none, moderate, severe).	Living in Ireland (LII) survey for 1995 through 2001.	3,573 households over the 1995–2001 panel	Expenditure equivalence	Standard of Living approach	All costs
Cullinan, J., Gannon, B., & O'Shea, E. (2013)	Ireland	Adults aged 65 and older	Presence of a disability or long term health condition (yes or no) and if yes, presence of a limitation in daily activities (none, moderate, severe)	Living in Ireland (LII) survey data 2001.	2,788 households	Expenditure equivalence	Standard of Living approach	All costs
Godfrey, A. J. R. & Brunning D. M. (2009)	New Zealand	Adults	blind, deaf-blind and vision-impairment	Telephone-based quantitative survey data 2004	200 individuals	Goods and services used, Goods and services required	Descriptive Analysis and focus groups.	Cost of taxi use
Jones, A., & O'Donnell, O. (1995)	UK except Northern Ireland	Households whose heads are non-retired and aged under 65.	Physical functioning	1986-87 Family Expenditure Survey (FES) Disability Survey.	5,060 households.	Expenditure equivalence	Equivalence scales; Regressions	Costs of nondurable assets: fuel, transport, services, food, alcohol, clothing, and other goods.
Ke, K. M. (2010)	UK	Adults aged 50 and older	Individuals with a diagnosis of nvAMD (Neovascular age- Face-to-face interviews 2006 related macular degeneration) in at least one eye, and not cognitively impaired		211 participants	Goods and services used	Descriptive Analysis	Costs related to eye treatment, related falls and accidents, dietary supplements, outside help (personal and state), transport costs for eye appointments, and other out-of-pocket expenses.
Loyalka, P., Liu, L., Chen, G., & Zheng, X. (2014)	China	All ages	Visual, hearing, speech, physical, intellectual, and/or mental impairment	2006 Second National Survey of Disabled Persons	771,797 households and 2,526,145 participants	Expenditure equivalence	Standard of Living	All costs
	US		Respiratory diseases including asthma and chronic sinus	Aid to Family with Dependent Children	341 families with disabled	Goods and services used	Regression (multivariate model)	Costs other than childcare and

Lukemeyer, A., Meyers, M. K., & Smeeding, T. (2000)	Children under age 18 in families on welfare	infections, arthritis, deformities, and diseases causing muscle weakness, visual or hearing impairments, all behavioral and learning disorders including ADHD, mental retardation and developmental disabilities including autism, mental and emotional illness and individual with daily activity limitations or functional limitations.	(AFDC) Household Survey, 1995 wave	children on AFDC as of 1992	disability-related expenditure for child care
Mitra, S., Findley, P. A., & Sambamoorthi, U. (2009)	Adults aged between 21 and 61		Medical Expenditure Panel Survey (MEPS) 1996, 1998, 2000, 2002, and 2004	10,987 individuals in 1996, 11,407 in 1998, 12,082 in 2000, 18,854 in 2002 and 16,459 in 2004.	Costs related to healthcare

* (In spanish) Tiene alguna enfermedad cronica o alguna incapacidad o deficiencia cronicas?, and if yes, ¿Se ha encontrado limitado en el desarrollo de su actividad diaria durante los ultimos seis meses debido a un problema de salud?.

expenditures, medicine, healthcare and/or specialized aid services. Other studies measure non-medical costs such as transportation or costs for daily activity assistance.

Descriptive analyses

Table 2 gives an overview of results of studies with descriptive and/or mixed methods studies. Costs refer to private costs born by individuals or households. There is a wide range of estimated annual mean total costs, from a minimum of USD 1,170²⁰ to a maximum of USD 6,952.²⁴ A wide range of mean costs can also be found by type of costs. For instance, health costs vary from a low of USD 137 for children with disabilities in the US²⁵ to a high of USD 2,614 for older adults with visual impairments in the UK.²⁴ Median costs are available in only a few studies, and are consistently below the mean, indicating a distribution of costs that is skewed to the right.

It should be noted that the studies that make it possible to calculate the extra costs of disability as the difference between mean (or median) costs between persons with and without disabilities^{25–27} tend to have lower estimates of extra costs, compared to studies that consider the costs incurred by persons with disabilities as the costs associated with a disability.²⁴ The latter studies are thus likely to give overestimates of costs associated with disability when these costs relate to general items that any household may need (e.g., health care, food), but not when they refer to disability-specific items (e.g. specialized aid).

The studies find that elderly people with disability experience relatively higher transportation costs and out-of-pocket expenditures compared to other age groups including people aged 16 and above and children aged below 18. Using descriptive analysis in the US, two studies^{15,28} show that elderly people with disability have a wider range of extra costs compared to other age groups.

In the column of other relevant results, the three studies that use the *goods and services required* approach find that a significant percentage of study participants report unmet needs. For instance, one study²² reports that 44% of participants report USD 2,889 of unmet needs and another study²⁰ finds a similar proportion (45%) of parents of children with disabilities felt that their children did not receive equipment or services due to lack of money to pay for it. Yet another study²¹ finds that people with disabilities incur USD 577 of transportation costs, but would require USD 1,822 of transportation costs if they were not constrained financially. Unmet needs due to financial or other constraints are translated into lower incurred costs. This is mentioned only by these three studies using the *goods and services required* approach, and is a reminder that if a study finds low incurred costs, that could imply that the needs of persons with disabilities are unmet.

Multivariate regression analyses

Table 3 presents results of studies that use a multivariate regression analysis. In the three studies with data on persons with and without disabilities, all else being equal, a disability is associated with higher out-of-pocket health expenditures. A severe disability for a child increases the probability of spending by 30% points, everything else held constant.²⁹ After controlling for gender, race/ethnicity, age, marital status, region, education, employment, poverty and health conditions, having a disability is associated with an increase of 65% in out-of-pocket expenditures for persons with disabilities in a working aged sample in the US.²⁶ Adopting an equivalence scale approach, physical disability is shown to have a significant effect on household fuel and transportation costs among households with elderly household heads in the UK.³⁰ The largest and most significant scale is for fuel, with a point estimate of 1.64,

implying relative consumption costs 64% higher for a two-adult household with a disability compared to a similar household without a disability.

In Vietnam, persons with disabilities above the age of five spend 78% more than persons without disabilities at public inpatient facilities than their counterparts without disabilities.²⁷ No discernible difference in spending by disability status was observed at public outpatient facilities in Vietnam.

Other studies in Table 3 use samples of children/adults with disabilities only. One study²⁰ finds the severity of disability to be the largest predictor of a range of out-of-pocket expenditures for children with disabilities in Canada, including prescription or non-prescription drugs, the purchase or maintenance of specialized aids, help with everyday activities, health care services, and transportation. The same study²⁰ also finds higher costs associated with a severe or chronic disability, and for children with health insurance. Another study²⁵ finds higher costs in households with higher income in the US.

Standard of living approach

Table 4 presents results of the eight papers that use the SOL approach. Three out of nine papers that adopt the SOL approach estimate extra costs of disability in local currency. The range of estimated extra costs of disability converted to 2010 USD prices is from USD 7137 for elderly households in Ireland to USD 44,064 for a non-pensioner couple where both are disabled in the UK. Given highly varying income levels and the potential varying burden of extra costs relative to income, papers present results as a percentage of income.

The estimated extra costs of disability as a proportion of average annual income ranged from 12% in Vietnam to 40% for elderly households in Ireland, as shown in Fig. 1. As stated above, some of these differences can result from differences in the availability of goods and services.

Five papers that adopt the SOL approach present estimates by the severity of disability. A severe disability is consistently associated with higher extra costs in all of these studies.

Results also vary by age and household composition. In contrast to descriptive findings of higher disability costs associated with elderly age, disability costs over the life cycle estimated using the SOL approach are mixed depending upon household composition. For the UK, a study⁴ shows higher costs for single pensioner versus non-pensioner households with disability (7.7% versus 4.5%) but results do not hold for couple households. In China, higher costs are associated with households with children versus adults with disability but not for single-adult households.¹⁴

The China study also estimated the extra costs across different types of disability and rural and urban location.¹⁴ They find large differences in costs depending on the type of disability. Another notable finding is the lower estimates for rural households. For instance, for a one-person household with a person with a severe hearing impairment, extra costs are twice as large in urban areas compared to rural areas.

Several applications of the SOL method show that estimated disability costs vary significantly according to the composition of the household. In the UK, for both non-pensioners and pensioners, the estimated extra costs as a percentage of income are higher for single-adult households than for couple households.⁴ Higher costs are observed when both individuals in the couple are disabled versus one (non-pensioner households only). Similarly in Ireland,¹⁹ single person elderly households spent more income on disability related items than couple elderly households (49% versus 40%). In China, disability costs descended in size among one-adult, two-adult and three-adult households.¹⁴

Discussion

We conducted a systematized review of the literature on the extra costs of living with a disability. To our knowledge, this is the first such review that covers studies across disciplines, methodologies and regions. We find that there is a small but growing, largely quantitative body of work that seeks to measure the extra direct costs of disability. There is considerable heterogeneity in data, measures and methods, which makes the comparison of their results challenging.

Despite this heterogeneity, a consistent pattern emerges in the distribution of costs. The evidence points toward individuals with disability having sizeable extra costs. These direct costs are consistently found to vary according to the severity of disability, life cycle and household composition. Higher costs are observed among persons with severe disabilities including higher overall disability costs, health-related expenditures, assistance with daily care costs, and transportation costs. Higher costs are also observed among persons with disabilities who live alone or in small sized households. This may be explained by greater reliance upon private care-giving and transportation services due to more limited informal care-giving and transportation support provided by the household.

Disability costs over the life cycle are more complex and depend upon the composition of the household and context. In China, higher costs are observed for households with children versus adults with disabilities but this reverses for households with a single adult living with disability whereas in the UK and US highest disability costs appear to be associated with old age.^{4,14,15,28} In the absence of strong social and health protection systems, households in China may outlay more resources to younger and working aged members with disabilities relative to older members with disabilities due to economic and other incentives associated with their rehabilitation. In countries with technologically advanced health systems, such as the US and UK, disability costs may increase with age and specialized health care needs which are not covered under national health insurance systems.

Overall, findings concerning the sizable and heterogeneous disability costs stress the importance that variation in needs are taken into account in the determination of poverty thresholds and benefits for the disabled population. Quantifying the extra costs of disability and adjusted poverty rates can assist policy makers in allocating sufficient resources to provide disability support services in accordance with their obligations under national and international disability law. It can also provide a basis for devising eligibility and benefit levels for disability support programs and in assessing the adequacy of supports. Several studies reviewed assessed estimated disability costs against the receipt of income support from Government. In the UK and China, public transfers have been found to fall significantly short of disability cost estimations.^{4,14} These preliminary findings suggest that public support programs are not sufficiently taking into account the extra costs associated with a disability.

An additional finding from the review relates to the low overall disability costs estimated in low- and middle-income countries. Cost estimates of all age samples of 9–12% in Vietnam and 14% in Bosnia are comparable to the estimate of 8% for households with three or more adults in rural China.^{14,31,32} This may reflect broader concerns for people with disabilities: it may be explained by relatively low level of household resources to devote to disability-related costs or lower levels of availability of, and accessibility to, disability goods and service markets such as rehabilitation services. Stronger family and community networks to care for people with disabilities may exist compared to high-income countries. Overall living standards may be low which may further mitigate the extent of disability costs estimated under a SOL approach. In China, across

Table 2
Descriptive statistics on annual extra costs in 2010 PPP USD.

Type of Cost/Reference	Country	Age groups	Extra cost estimate in USD per year in 2010 PPP		Other relevant Results	
			Mean	Median		
All Extra costs						
Ke, K. M. (2010)	UK	Adults 50 and older	USD 6,952 Moderate	USD 7,541 to 10,001 Severe	USD 6562	Non-medical cost accounts for 38% of average annual direct costs per person.
Stallard, E. (2011)	US	Adults 65 and older	lifetime USD 103,690			
Burton, P., & Phipps, S. (2009)*	Canada	Children aged 5-14	USD 1,170			
Total Health Costs						
Burton, P., & Phipps, S. (2009)*	Canada	Children aged 5-14	USD 1,169		USD 504	44.7% of parents of children with disabilities feel their children did not receive equipment or services due to a lack of money to pay for it.
Ke, K. M. (2010)	UK	Adults 50 and older	USD 2,614			Mean out-of-pocket expenditures is 50% higher for children with disabilities. The distribution of out-of-pocket expenditures is highly skewed: the upper decile accounts for 85% of out-of-pocket expenditures.
Lukemeyer, A., Meyers, M. K., & Smeeding, T. (2000)	US	Children under age 18	USD 1,847			
Mitra, S., Findley, P. A., & Sambamoorthi, U. (2009)+	US	Adults aged 21 to 61	USD 1,102		USD 488	
Newacheck, P. W., Inkelas, M., & Kim, S. E. (2004)+	US	Children under age 18	USD 137			
Palmer, M. G., & Nguyen, T. M.T. (2012)+ Stallard, E. (2011)++	Vietnam US	People aged 5 and older Adults 65 and older	USD 595	For persons in the community, the average cost of out-of-pocket for community care ranges from USD 228 (CI) to USD 1441 (ADL)		
Costs of assistance with daily activities						
Stum, M. S., Bauer, J. W., & Delaney, P. J. (1998)	US	Adults 65 and older	USD 4,366		USD 738	Home care expenditure levels are highly skewed; 10% of disabled elderly report paying more than USD 11,810
Burton, P., & Phipps, S. (2009)*	Canada	Children aged 5-14	USD 1,260		USD 808	44% of participants report USD2,888.6 of unmet need.
Wilkinson-Meyers, L., Brown, P., McNeill, R., Pats ton, P., Dylan, S., & Baker, R. (2010)	New Zealand	Adults aged between 18 and 64	USD 2751			
Stallard, E. (2011)	US	Adults 65 and older	Moderate USD 1,722 Severe	USD 52,555		
Transportation Costs						
Godfrey, A. J. R. & Brunning D. M. (2009)	New Zealand	Adults	USD 577 (actual)	USD 1,822 (required)		Lower income households with disabilities spend less on transport, perhaps because it is less essential than food and other necessities. Less than 20% of persons with disabilities report that they spend more on transport due to disability. This may be due to a lack of appropriate transport and possibly a reduced desire to travel.
Oxley, P.R., & Richards, M. J. (1995)	UK	Working age individuals	USD 179	Moderate USD 163 Severe	USD 209	
Burton, P., & Phipps, S. (2009)*	Canada	Children aged 5-14	USD 437		USD 202	19% of annual out of pocket expenditures
Specialized aid Costs						
Burton, P., & Phipps, S. (2009)*	Canada	Children aged 5-14	USD 898		USD 404	
Lukemeyer, A., Meyers, M. K., & Smeeding, T. (2000)	US	Children under age 18	USD 2,100			
Stallard, E. (2011)	US	Adults 65 and older	note: lifetime USD 103,691			For persons with severe disability in nursing home, annual average cost of nursing home varies from USD 5624 for person with cognitive impairment (CI) to USD 52,555 for persons with activity of daily living (ADL)

* Indicates a conditional mean.

Table 3
Results from multivariate regressions.

Type of Cost/Reference	Country	Age groups	Results from regression model
Total Health Costs			
Burton, P., & Phipps, S. (2009)	Canada	Children aged 5–14	Among children with disabilities, costs are significantly higher if the condition is very severe or chronic, everything else held constant. Families with no health insurance coverage spend much less on help. Affluent families spend more. For children with disabilities, the health costs increased by USD 1011, all else equal.
Ke, K. M. (2010)	UK	Adults 50 and older	Adjusted direct costs are significantly higher for males, those with mild/moderate visual impairment in both eyes and those with a recent diagnosis.
Lukemeyer, A., Meyers, M. K., & Smeeding, T. (2000)	US	Children under age 18	A moderate/severe disability increases the probability of spending by 18/30% points respectively. The type of disability had no significant effect.
Mitra, S., Findley, P. A., & Sambamoorthi, U. (2009)	US	Adults aged 21 to 61	Health costs for persons with disabilities is 65% higher than persons without disabilities, all else equal.
Newacheck, P. W., Inkelas, M., & Kim, S. E. (2004)	US	Children under age 18	Among children with disabilities, compared with children in the highest income families, children in <200% FPL had 59% lower out of pocket costs, and those in 200–399% FPL had 31% lower out of pocket costs. Out of pocket expenses for insured children were 46% lower than those of uninsured children.
Palmer, M. G., & Nguyen, T. M.T. (2012)	Vietnam	People aged 5 and older	A disability increased public inpatient expenditures by USD 105, and public outpatient expenditures by USD 15, all else equal.
Costs of assistance with daily activities			
Burton, P., & Phipps, S. (2009)	Canada	Children aged 5–14	For children with severe disabilities, the cost of assistance increased by USD 2969 annually compared to other children with disabilities, all else equal.
Transportation and fuel costs			
Burton, P., & Phipps, S. (2009)	Canada	Children aged 5–14	For children with severe disabilities, the cost of transportation increased by USD 356 annually compared to other children with disabilities, all else equal.
Jones, A., & O'Donnell, O. (1995)	UK	Households whose heads are non-retired and aged under 65.	Costs of fuel and transportation are 45% and 64% higher respectively for a two-adult household with a disability compared to a similar household without a disability.

both households with adult and children with disabilities samples, there exists a large rural-urban divide in disability costs suggesting that the above factors contributing to low disability costs may be compounded in rural areas.¹⁴

This review has identified a number of limitations with the existing literature on disability cost estimation and opportunities for further research.

First, the evidence is limited to only 10 countries that account

for a small share of the global population with disabilities. More studies are needed using nationally representative and rigorous quantitative methods that at the very least, adjust costs for observed characteristics (e.g. age, sex, rural/urban residence) through multivariate analysis. More quantitative studies are not feasible unless more internationally comparable disability data is collected through mainstream data collection instruments that provide global information through inclusion of tools such as the

Table 4
Estimated total costs associated with disability in studies using the Standard of Living Approach.

Reference	Country	Age groups	in USD per year in 2010 PPP	As % average income in data year	Other Relevant Results
Brana, J-P., & Anton, J-I. (2011)	Spain	Adults aged 17 and older		Moderate 40% Severe 70%	
Braithwaite, J., & Mont, D. (2009)	Bosnia Vietnam	All ages All ages		14% 9%	
Cullinan, J., Gannon, B., & Lyon, S. (2011)	Ireland	All ages	USD 8,362 Moderate USD 6,901 Severe USD 10,319	23% Moderate 30% Severe 33%	In the short term, Moderate 20% Severe 37%
Cullinan, J., Gannon, B., & O'Shea, E. (2013)	Ireland	Adults aged 65 and older	USD 7,137 Moderate USD 3,672 Severe USD 14,775	40%	
Loyalka, P., Liu, L., Chen, G., & Zheng, X. (2011)	China	All ages	NA	For households with disabled adults: 8%–43% For households with disabled children: 18%–31% Moderate –3% to 116% Severe –14% to 158%.	
Mont, D., & Cuong, N. V. (2011)	Vietnam	People aged 5 and older	NA	12%	
Saunders, P. (2007)	Australia	Adults aged 65 and older	NA	29% Moderate 30% Severe 40%	
Zaidi, A., & Burchardt, T. (2005)	UK	Adults aged 16 and older	USD 13,262 to USD 44,064 Moderate USD 5882 to USD 31,872 Severe USD 11,123 to 58,395	Mild 11% Moderate 34% Severe 64%	For non-pensioners and pensioners, the estimated extra costs are higher for single- adult households than for couple households. Extra costs for persons with a low severity of impairment range from USD 1,925 (pensioner couple households, one disabled) to USD 10,267 (non-pensioner couple households, two disabled).

Washington Group short set of questions³³ and through disability-specific data collection efforts for data on disability-specific services. Including the Washington Group Short Set of questions in internationally comparable surveys such as the Luxembourg Income Study (LIS), the Demographic and Health Surveys (DHS) or the Living Standard Measurement Survey (LSMS) would provide necessary data for internationally comparable estimates of extra costs of disability in many countries and perhaps globally.

It is also notable that the majority of studies in this review originated from high-income countries. There exists a clear need for additional research from LMICs. This need is particularly acute given that the vast majority of the world's disabled population is estimated to live in LMICs where formal systems of social protection are less developed.¹ There exists a significant gap in understanding how disability leads to extra costs of living and poverty in LMICs, which has direct relevance to informing the design of social protection programs. Preliminary evidence presented in this review suggests that disability costs are lower as a proportion of household income in LMICs relative to high-income countries. This finding likely reflects the lesser availability of disability-related goods and services, and serves as an important reminder that much work remains to be done in protecting the rights and meeting the needs of persons with disabilities worldwide.

In addition, the vast majority of recent quantitative studies adopt the SOL approach. Whilst the SOL approach may carry advantages, it is not without limitation. Chief among these are that the method is sensitive to the choice of SOL measure (i.e., the method of measuring and constructing an SOL measure such as the asset index) and assumptions regarding the statistical model linking the SOL, disability and income variables. For the latter reason, one study recently³⁴ advocated a non-parametric matching method as an alternative method to test the sensitivity of SOL approach results. Whether the SOL approach is adopted using parametric or non-parametric means, there remain additional problems associated with measurement error of disability and endogeneity bias.

Disability measures traditionally are subject to a range of measurement biases such as respondents not interpreting questions related to the nature and type of disability correctly, sampling error, and exogenous characteristics of respondents which influence reported disability status such as socioeconomic status.³⁵ If issues regarding measurement bias, omitted variables and reverse causality are not addressed then estimated parameters will be biased and inconsistent. Among the studies reviewed, only one¹⁷ applied longitudinal data that could address these bias concerns. There is a need for longitudinal research to disentangle the links between disability and extra costs. Longitudinal research could explore the dynamics of disability costs including the long- and short-term nature of disability costs, and the costs of transitioning into and out of disability. None of the studies under review considered the dynamics of disability and costs. Disability can also be permanent, temporary or intermittent, which can impact the experience of additional costs.

Future quantitative studies on extra costs also need to consider the impacts of policies and programs that may affect such costs. For example, one study in Canada²⁰ with universal health coverage had similar extra health care costs estimates compared to another study in the U.S.²⁷ without universal health coverage. Policies and programs that may reduce extra costs such as health insurance programs and pension or cash transfer programs need to be evaluated in their ability to mitigate the cost burden for persons and households with disabilities. In LMICs, in particular, there exist very few robust impact evaluations concerning disability, whether general or disability specific programs, and this should be as a priority area for future research.

Unmet needs are another consideration that most studies conducted so far have not covered. Indeed, the issue of extra costs cannot be considered independently of a study of needs and environments, as extra costs can be limited due to financial constraints and barriers in the environment, and thus be inversely related to unmet needs. Indeed, one study did find evidence of higher costs associated with higher income.²⁵ Finding low estimates for extra costs is not necessarily a positive signal regarding the wellbeing of persons with disabilities.

More broadly, there is a need for more qualitative research into the economic costs of disability, as well as on unmet needs and barriers to goods and services to complement the quantitative methods. Most of the evidence so far is quantitative and thus focuses on costs that large data sets collect such as health care costs. All but two of the papers reviewed adopted quantitative methods. The disadvantage of using individual interviews and focus groups is inherent to qualitative methods applied on a small scale. Results cannot be generalized, and one could be concerned about relying exclusively on individual interviews or focus groups to estimate extra costs. However, such approaches can be critically important in raising key issues and concerns that can be further explored by mixed methods or quantitative research approaches. Qualitative research can also be especially important to determine the consequences of extra costs and identifying unmet needs. Qualitative data can also provide evidence when quantitative data is not available. Qualitative research also is particularly suitable to collect cost data on disability-specific items (e.g., assistive devices) and for studies using the *goods and services required* approach or the *goods and services used* approach.

In addition, participatory research methods were not used in the 20 studies under review. Participatory research involving Disabled People's Organizations (DPOs), persons with disabilities and disabled researchers could bring insights from the lived experience of persons with disabilities and could facilitate linking costs to other issues such as environmental barriers or unmet needs. Both qualitative and participatory research could also facilitate understanding of the complex linkages between extra costs and foregone employment opportunities. As noted in a broad study of economic wellbeing in Vietnam,³⁶ the analysis of the economic impact of disability on individuals and households from both qualitative and quantitative data, is a relatively unexplored area of research that can offer new insights. For instance, a person with no access to affordable or adequate assistive devices would have limited extra costs, but would have unmet needs that may lead to foregone earnings and to further deprivations. This larger and complex picture of the economic lives of persons with disabilities has rarely been considered so far. Qualitative and participatory research could contribute to filling this gap.

Finally, although the review above provides useful insights on the state of knowledge on the extra costs of living with a disability, it is not without limitations. First, although we used a variety of search terms related to disability, we did not search the literature within specific impairments (e.g. autism). In addition, we did not include studies that were not published in peer reviewed journals. There is a grey literature on the extra costs of disability that warrants further exploration as well.¹²

Proposed agenda for further research

This review has identified several areas where there are gaps in research in the extra costs of disability, which are the bases for recommendations for further research:

- More quantitative evidence is needed using rigorous methods that adjust for differences in individual and household

characteristics. Most of the recent research uses the expenditure equivalence approach and the SOL methodology, which is not without limitations. More research is needed using other methodologies and longitudinal data. Extra costs also need to be rigorously assessed in how they are affected by programs and policies (e.g. universal health coverage).

- For more quantitative studies to be feasible, more data collection is needed using established tools, such as the Washington Group Short Set of questions, in international surveys such as DHS, LSMS and LIS and as part of disability-specific surveys with new methodologies such as the Model Disability Survey of the World Health Organization and the World Bank, now under development. International surveys can provide evidence on extra costs on general items such as health care, while disability-specific surveys can provide evidence on the accessibility of disability-specific goods and services and identify unmet needs.
- Research so far is mostly in high-income countries. More research is needed in LMICs because the costs of disability, the nature of barriers faced, and the availability of goods and services can be highly context specific.
- Extra costs so far have been studied often in isolation, while they are tied to several aspects of wellbeing and poverty. Linking them to the study of needs and environments would be a way to connect costs to broader issues of wellbeing. More specifically, future research on disability costs cannot ignore needs and the availability and accessibility of needed goods and services, in particular those goods and services that are particular to people with disabilities, such as assistive devices.
- More qualitative research on extra costs is needed. Most of the evidence so far is quantitative and thus focuses on costs that large data sets collect regarding information on issues such as health care costs. Qualitative research seems particularly suitable to collect cost data on disability-specific goods and services (e.g., assistive devices) and for studies using the *goods and services required* approach or the *goods and services used* approach.
- More participatory research is also needed. None of the studies had a participatory component. Partnerships with disabled people's organizations (DPOs), persons with disabilities and disability researchers are needed to identify issues related to extra costs and how they relate to other issues such as barriers to goods and services.

As the international policy community increasingly pays attention to the 1 billion persons with disabilities worldwide and their wellbeing, researchers can help fill these gaps.

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Conflict of interest

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Ethical approval

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