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"It Is Too Much for Us": Direct and Indirect Costs of Disability Amongst Working-Aged People with Disabilities in Dhaka, Bangladesh and Nairobi, Kenya

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ABSTRACT

Globally, people with disabilities face a heightened risk of poverty. Drivers of poverty include exclusion from work and other livelihood activities (indirect costs) and disability-related direct costs – such as for rehabilitation, personal assistance and assistive devices – that are required for participation and functioning. This research explores sources of direct and indirect costs, their impact and mitigation strategies using 42 in-depth interviews with working-aged people with disabilities in Nairobi, Kenya and Dhaka, Bangladesh. This research finds that people with disabilities and their households face high direct costs, such as for healthcare, assistive devices, transportation and accommodations at school and work, and indirect costs, such as un- and underemployment and lower salaries when working. Many direct costs were unmet, or covered through out-of-pocket spending, although social protection in Kenya was also an important strategy. Unmet direct costs frequently led to higher future indirect costs. Direct and indirect costs could cause financial strain, decreased participation, health and wellbeing, particularly when unaddressed. Challenges mitigating costs included not just insufficient income, but also lack of decision-making power within the household and insufficient information on and poor availability of needed goods, services and opportunities – factors which should be considered in the design of interventions.

KEYWORDS
disability; poverty; Kenya; Bangladesh; capabilities; extra costs

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Introduction

There is increasing recognition that people with disabilities face a heightened risk of poverty (Banks, Kuper, and Polack 2017; Mitra, Posarac, and Vick 2013). Disability is defined under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as including "… those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations 2006). While conceptualisations of disability vary, the capability approach is useful for understanding both disability and the relationship between disability and poverty (Mitra 2018; Sen 2009; Dubois and Trani 2009).

Under this approach, disability can be viewed as a deprivation in capabilities (opportunities to achieve desired functionings such as participating in school, work and social life) that arise from the interaction between an individual's impairment with resources (e.g. ownership or access to goods, services and information) and personal (e.g. age, gender) and environmental (social, political, economic and cultural) factors (Mitra 2018; Dubois and Trani 2009). For example, a person with a physical impairment may face barriers to working, depending not only on the type and severity of their impairment, but also on their resources (e.g. information about available jobs, having needed assistive devices), personal factors (e.g. having qualifications for desired jobs) and environmental factors (e.g. stigma towards disability, physical accessibility of workplaces and transportation, enforcement of anti-discrimination laws). As such, the extent to which an impairment leads to reduced capabilities – and thus disability – depends in large part on an individual's environment and resources. Addressing disabling environmental, personal and resource constraints (e.g. stigma of disability, inaccessible infrastructure and communication, lack of income) can in turn increase capability sets – and reduce the level of disability – for people with impairments (Dubois and Trani 2009).

Disability can lead to poverty through two key routes under the capability approach (Sen 2009). First, people with disabilities can face reduced capabilities in livelihood activities, what Sen calls "income-earning handicaps" (Sen 1992). These indirect costs have been well noted, with numerous studies finding people with disabilities and their households have fewer opportunities for decent work compared to people without disabilities (Palmer et al. 2015; Mitra, Posarac, and Vick 2013). Indirect costs of disability may be reflected in individual and household income, and explain why people with disabilities and their households are more likely to fall below poverty lines (Banks, Kuper, and Polack 2017).

Second, people with disabilities may face "income-using" or "conversion handicaps" in translating income and other resources into desired functionings

(Sen 1992; Sen 2009). A major source of conversion handicaps are the additional expenses – or direct costs – for goods and services required by people with disabilities (Mitra 2018; Mitra et al. 2017). For example, a person with a profound visual impairment and a person without a disability may both be educated, but achieving this functioning has been more costly for the person with a disability (e.g. paying for a screen readers/Braille texts, assistance to get to school). Direct disability-related costs include expenses for disability-specific items (e.g. rehabilitation, assistive devices, personal support) or additional spending on services also used by people without disabilities (e.g. transportation, general healthcare) (Palmer et al. 2015). The type and magnitude of direct costs can vary significantly amongst people with disabilities, for example by impairment, age and household composition, as well as the extent to which personal and environmental factors are disabling (Mitra et al. 2017; Allotey et al. 2003). In contrast to indirect costs, direct costs of disability are rarely captured in determinations of poverty, as most measures do not account for conversion handicaps and assume equivalent consumption needs (i.e. universal poverty line) between people with and without disabilities (Mitra, Posarac, and Vick 2013; Palmer 2011).

Direct and indirect costs of disability can be substantial and affect the economic wellbeing of people with disabilities and their households. For example, studies have found people with disabilities are much less likely to be working, and earn lower salaries when they do work, compared to people without disabilities (Mitra 2018; United Nations 2019). Further, spending on direct disability-related costs as a proportion of household income have been estimated at 9–9.5% in Vietnam (Braithwaite and Mont 2009; Minh et al. 2015), 14% in Bosnia and Herzegovina (Braithwaite and Mont 2009), 19% in Cambodia (Palmer, Williams, and McPake 2019), 8–43% in China (Loyalka et al. 2014) and 16–155% across 31 European countries (Antón, Braña, and de Bustillo 2016). These estimates of direct costs only capture actual spending, not necessarily all spending required for full participation. People with disabilities often require goods and services that are unaffordable or unavailable in their area (Hanass-Hancock et al. 2017; Palmer et al. 2015), which may explain why estimates tend to be higher in high income compared to low- and middle-income countries (LMICs) (Mitra et al. 2017). Unmet needs for disability-related goods and services can have profound implications for the health, well-being and participation of people with disabilities and their households (Allotey et al. 2003).

Additional research is needed to identify sources of direct and indirect disability-related costs, their impact and how they are managed by people with disabilities and their households. To begin to fill these gaps in knowledge, this study uses in-depth interviews with working-aged people with disabilities in two urban centres – Dhaka, Bangladesh and Nairobi, Kenya.

Study Context

Kenya and Bangladesh have both ratified the UNCRPD (United Nations Enable 2016). Estimates of disability prevalence in both countries vary widely depending on the methods used for measuring disability. For example, disability prevalence (in ages 5+) was estimated at 2.2% in Kenya in the 2019 national census and 6.9% in Bangladesh in the 2016 Household Income and Expenditure Survey, both of which used the Washington Group Short Set questions (Development Initiatives 2020; The Disability Data Portal 2019). The World Health Survey 2002–2003 estimated that the prevalence of disability amongst working-age adults (18–60 years) was 8.3% in Kenya and 18.8% in Bangladesh (Mizunoya and Mitra 2013). In both countries, studies have found that people with disabilities are less likely to be working (Mizunoya and Mitra 2013), have lower educational attainment (Mitra, Posarac, and Vick 2013) and are more likely to be living below the national poverty line (The Disability Data Portal 2019) compared to people without disabilities.

Both countries have disability-targeted social protection entitlements aimed at addressing poverty and disability-related costs (Hameed 2019). People with disabilities must be registered as having a disability according to national definitions to receive any of these entitlements. In both settings, it is likely that only a small proportion of all people with disabilities are registered: based on registration figures and national disability prevalence estimates, it is estimated that 7% of people with disabilities in Kenya and 11% in Bangladesh are registered as having a disability.

In Bangladesh, entitlements include a disability-targeted, means-tested cash transfer of 750 BDT (US$8) per month, available to people with disabilities in households with an annual income below 24,000 BDT (US$284). People with disabilities may also access a 5% reservation at training institutions and a 10% quota for public sector jobs for people with disabilities and orphans. However, the quota had been suspended at the time of data collection.

In Kenya, a cash transfer of 2000 KES (US$20) per month is available for people with severe disabilities (requiring full-time caregiving support) living in poor households (no member is earning an income, receiving a pension or another cash transfer). People with disabilities in Kenya are also eligible for income tax exemptions if they are employed in the formal sector with an annual income of less than 150,000 KES (US$1450) and free or subsidised assistive devices and education scholarships through the National Development Fund for Persons with Disabilities. People with disabilities may also utilise job placement services run by the National Council for Persons with Disabilities, a 5% quota in public and private sector jobs and a 30% quota (shared with women and youth) of government procurement opportunities. Finally, people with and without disabilities in Kenya can access social health insurance through the National Hospital Insurance Fund (NHIF).

Methods

This research used a qualitative study design with in-depth interviews to explore direct and indirect disability-related costs amongst working-aged adults with disabilities in Dhaka, Bangladesh and Nairobi, Kenya. Specific objectives of this research included: (a) to identify sources of direct and indirect costs, and factors affecting their magnitude; (b) to describe coping strategies used to manage these costs and (c) to assess the impact of costs on the lives of people with disabilities and their households.

Study Setting

Data collection took place in Nairobi and Dhaka, which are large capital cities. This research was embedded within the Innovation to Inclusion (i2i) project, which is trialling an inclusive employment programme for people with disabilities in these settings. As such, the research settings were selected to inform its development.

Sampling

Purposive samples of working-age adults in Nairobi (n = 22) and Dhaka (n = 20) were selected for representation by age, gender, work status and impairment type (Table 1). Participants were recruited with the assistance of local Disabled Peoples' Organisations (DPOs), non-governmental organisations (NGOs) working on disability and other networks (e.g. Bangladesh Business and Disability Network).

Participants were contacted via phone and invited to partake in the study. Overall, 20 of 24 people in Dhaka and 22 of 25 in Kenya agreed to participate.

Table 1. Characteristics of study participants.

Characteristic	Bangladesh (n = 20) # (%)	Kenya (n = 22) # (%)
Gender		
Female	10 (50%)	11 (50%)
Male	10 (50%)	11 (50%)
*Impairment type**		
Physical	7 (35%)	8 (36%)
Hearing	6 (30%)	6 (27%)
Vision	4 (20%)	5 (23%)
Intellectual	3 (15%)	2 (9%)
Psychosocial	3 (15%)	4 (18%)
Albinism	–	2 (9%)
Epilepsy	–	2 (9%)
Age		
Range (average)	19–61 years (33 years)	19–50 years (36 years)
Work status		
Working	12 (60%)	17 (77%)
Not working	8 (40%)	5 (23%)

*Total is more than 100% as some respondents had multiple impairments.

Data Collection

Data was collected in December 2018 in Dhaka and January 2019 in Nairobi. Interviews were conducted at a location of the participant's choosing.

Semi-structured interview guides included questions on: (a) participants' experience in accessing education, health and work, including associated direct and indirect costs; (b) how costs were managed and (c) impact of costs. Interviews were approximately an hour in length. Interviews were conducted in Bangla in Bangladesh and predominantly in English, with some in Kenyan Sign Language and Kiswahili, in Kenya. All interviews were recorded, transcribed and translated.

Research Team

Interviews were led in Kenya by LMB and EN and in Bangladesh by LMB with translation support. The researchers (LMB, EN) both have extensive experience in qualitative methods and disability research. No member of the research team had prior relationships or interactions with study participants before the interview.

Analysis

During data collection, the research team held regular debrief sessions to discuss emerging themes and identify gaps in the interview schedule. An additional researcher (SH), who was not involved in data collection but was working on similar research, was also consulted for an alternative point of view to reduce researcher bias.

Thematic Analysis was used to analyse data. An initial coding framework was developed inductively after reviewing transcripts and interview notes. Transcripts were coded using NVivo 11, and codes grouped into themes and sub-themes. Comparisons and inter-relationships between themes and categories (e.g. by study location and individual characteristics such as impairment type, gender) were conducted throughout the analysis (Green and Thorogood 2018).

Ethical Considerations

Ethical approval for this study was obtained from the LSHTM in the UK, the National Commission for Science, Technology and Innovation in Kenya and the Centre for the Rehabilitation of the Paralysed in Bangladesh. Informed written consent was received from all participants. Sign language interpretation, simplified information sheets and other adaptations were available to support inclusion. Proxy respondents (e.g. caregiver) were used in a few instances to supplement interviews for people who faced significant difficulty communicating with available adaptations (e.g. people with severe intellectual impairments).

Results

Sources of Direct and Indirect Costs

Direct Costs

(1)#Health- and Functioning-related Costs. Healthcare was one of the largest and most frequently cited sources of direct disability-related costs in both settings. Respondents reported high levels of spending for services (e.g. rehabilitation, surgery, psychiatry), assistive devices, and for some general healthcare (e.g. pain management) linked to their impairment.

Costs were typically highest at the onset of impairment, as participants reported visiting multiple providers to obtain a diagnosis and receive needed services (e.g. surgery, intensive care following an accident or illness). For a few participants, such as people with profound hearing impairments who were not suitable candidates for hearing aids, health-related costs were minimal afterwards. However, most people required ongoing healthcare after impairment onset. In particular, people with psychosocial impairments, epilepsy and albinism needed to continually pay for medications and protective products (e.g. sunscreen).

> The older generation of medication is cheap, it will cost anywhere between let me say, let me just say 500 and 1000 shillings per month [US$5–10], but the new generation of medication would certainly cost you between 2000 [US$20], and 5000 shillings [US $50]. And maybe you are talking about one medication and a person is on different kinds of medication. So you try looking at the cost even for the people who are using cheap medication, it’s not really cheap for them, these are people who have no source of livelihoods and are dependent on their families …
>
> Man with a psychosocial impairment, Kenya

Assistive devices were also a large cost for many participants. In addition to the initial purchase, most reported continual repair and replacement costs. For example, a woman with visual impairment in Kenya explained that she replaced her walking cane three times in the last year because “ … *you buy one, then you walk around, then in the streets people step on them and then they break so you have to keep buying*”. Each replacement was 1000 KES (US$10). Another man with a hearing impairment in Kenya had not replaced his hearing aids after misplacing them two years earlier because he couldn’t afford the required KES 50,000 (US$490). He had received the first one for free from a charitable organisation, but explained: “ … *most people lost them and now they haven’t [got hearing aids] … because if you lose, now the responsibility is yours*”.

(2)#Accommodations for Participation. Participants faced many direct costs due to non-inclusive environments in work, education and social life.

For education, some participants reported higher fees to attend school or trainings, such as tuition for special schools rather than free, but inaccessible public schools. Additionally, in Kenya, a woman with albinism and profound visual impairment had to pay more than twice the standard fee for a computer course because she required adaptive technology. Several participants also reported attending multiple training courses, as they had to change fields after onset of disability in adulthood, or because their previous trainings were of little use in finding jobs. For example, a woman with visual and physical impairments explained that she'd taken training courses in computers, counselling and baking, but had "*… been trying to apply for jobs … but with no outcome*". Her most recent course involved tuition (KES 25,000; US$240) and daily taxis for her and her personal assistant (KES 2000/US$19 per day). Other reported expenses included exam writers or for audio versions of textbooks for people with visual impairments.

Participants also reported work-related costs, such as adaptations to facilities (e.g. accessible toilets, ramps) and communication strategies (e.g. sign language interpretation, Braille, screen readers) – although these costs were rarely met. Some participants needed assistance to navigate inaccessible processes linked to work. This assistance was usually covered as an indirect cost by family (i.e. forgoing time on work or other activities to provide assistance), but in some instances involved direct costs. For example, a woman with a visual impairment in Kenya had to hire an assistant to guide her to vendors outside her area and carry heavy bags of rice. In addition to the salary costs for this assistant, she faced frequent losses of income from assistants taking advantage of her impairment and misreporting profits.

Additional transportation costs were widely reported, particularly by people with mobility limitations. Participants often perceived that they had a higher need for transportation than people without disabilities, as they required frequent travel to health services, or, for people with visual and physical impairments, could not walk long distances. Some participants with mobility limitations also reported having to pay higher rates to travel similar distances as a person without a disability. For example, in Kenya, a participant with a mobility limitation reported having to pay *matatu* drivers a higher rate "*… because sometimes they're in a hurry and they want people to get in quickly … sometimes you have to give the conductor an extra shilling for them to be patient with you*". Additionally, a few participants were unable to use public transportation at all because of its inaccessibility, and so relied on more expensive private options or remained restricted geographically.

Indirect Costs

(1)#Amongst People with Disabilities. People with disabilities faced losses in earnings and time due mainly to environmental factors that constrained participation in work, school and social life.

For example, the interaction between impairments, personal and environmental factors could affect the quantity, quality and timing of school and training. Many participants experienced late starts and interruptions to their schooling due to onset of disability, ongoing health and rehabilitation needs or household financial difficulties. Due to these and other challenges (e.g. difficulties getting to school, discrimination), many participants had either not attended school, dropped out or finished school later than their peers without disabilities. Other participants, particularly people with sensory or intellectual impairments, remained in school but were excluded from the learning process. For example, a woman with an intellectual impairment in Kenya attended a training apprenticeship for 2 years, but did not gain a certification or useful skills and was not paid during her tenure as "*teachers were … telling us 'you are idiots why give you money. To do what!*'" The level and quality of education and training in turn could affect job opportunities, while delayed finishes meant later entry into the workforce.

Even participants who had the necessary skills and qualifications reported consistently being denied jobs, due to discrimination, inaccessible environments, lack of accommodations and low expectations from employers, family and even themselves. Consequently, some participants remained unemployed, or more frequently, engaged in low paying, unstable work in the informal sector. For example, a woman with a hearing impairment in Bangladesh explained that she was earning much less than peers without disabilities on her Masters' course because she had opted for a job with an NGO rather than in the private sector. She explained her decision resulted from fear that private sector employers would not be accepting of her disability: "*[s]omebody may shout at me, somebody may say bad words to me if I make any mistakes*". Another woman with a physical impairment in Kenya with a post-secondary diploma and over a decade work experience recalled the difficulties of applying for jobs after being made redundant:

> [W]hen you get into the interview room, you just see the facial expressions, it's like 'is she going to do it?', and at times you hear, 'we didn't know that you are a person with disability.' You see it is very discouraging … you just know that they disqualified me maybe because of the disability.
>
> Woman with a physical impairment, Kenya

She has been unemployed for three years, while most of her other 35 former colleagues without disabilities who were made redundant at the same time have found work.

The effect of disability on earnings was clearest for people who experienced onset of disability during working years. These participants often took time out of work for diagnosis and treatment. Upon returning to the workforce, they noted a dramatic decline in their work opportunities, including the types of jobs they could get, and their earnings. For example, one man with schizophrenia in Bangladesh explained that he previously worked for a company where he had a fixed contract, earned a 16,000 BDT(US$188) monthly salary and was provided with benefits such as a motorbike and phone data. After the onset of schizophrenia, he resigned from his job after feeling that the "*CEO was not in a mood to keep me*" and to seek psychiatric services. He has since been cycling between unemployment and unsteady jobs in the informal sector at half of his previous salary.

Finally, navigating inaccessible processes and accessing needed services led to indirect costs for people with disabilities. For example, people with mobility limitations in both settings spent longer commuting because of the lack of accessible transportation, which could affect their working hours and their decision if and where to work. Further, people had to take unpaid absences from work to seek healthcare or due to poor health.

(2)#Amongst Family Members. Indirect disability-related costs were also borne by family members without disabilities to help manage the disabling barriers they faced in everyday life. For example, a woman with a visual impairment in Kenya explained that she can fill in online applications by herself using her screen reader, but requires assistance from her mother for paper applications. Other participants described family members accompanying them to doctors' appointments or while using public transportation. Particularly in Bangladesh, family played an important role in helping participants overcome barriers to finding work (e.g. identifying an employer willing to hire people with disabilities, preparing application materials, traveling to application points on their behalf).

A few family members of participants had stopped or decreased their working hours to provide more extensive caregiving support. For example, the mother of a young man with autism in Bangladesh explained that she "*… used to work before I acknowledged his problem. I left my job when I became aware of it*".

Coping Strategies

It is important to note that most participants were not able to meet the direct costs for all the goods and services they required, and were unable to avoid at least some indirect costs of disability. For costs that were overcome, respondents reported a range of coping strategies, described below.

(1)#Out-of-pocket Payments

All participants reported paying out-of-pocket for at least some portion of direct costs. Participants mostly managed these costs from their households' income and savings. To manage both direct and indirect costs, some participants reported borrowing from friends and extended family, or taking out loans (often with interest) from local businesses and lenders. For example, one woman in Bangladesh who acquired a physical impairment through a workplace accident explained that she now has to " … *borrow and pay and again borrow*" from local shopkeepers to meet her daily expenses due to her decline of earnings post disability onset. Similarly, the family of a man with a physical impairment in Bangladesh had taken out a 30,000 BDT (US$350) loan to finance his rehabilitation after spinal cord injury.

(2)#Social Protection

Social protection programmes were available in both settings to help cover direct costs (e.g. free provision of assistive devices, or improving capacity to pay for expenses through cash transfers, health insurance, tax exemptions) and indirect costs (e.g. improving work opportunities through the quota system, procurement schemes, cash transfers, tax exemptions). These programmes were accessed by some participants, mainly in Kenya.

For example, a few participants employed in the formal sector in Kenya reported using the income tax exemption (equivalent to 30% of gross salary). However, some noted that they faced difficult decisions between keeping this benefit or advancing to higher paying jobs, as this entitlement was only available to people earning below 150,000 KES (US$1450) per year.

Similarly, some participants were enrolled in the NHIF or private health insurance schemes in Kenya, which provided coverage for some healthcare needs (e.g. epilepsy and certain psychotropic medications, general healthcare). Still, participants reported high out-of-pocket spending on healthcare even with health insurance due to the inadequate coverage of disability-related health services (e.g. most forms of rehabilitation, assistive devices). For example, one man with a psychosocial impairment in Kenya reported that he was covered by both NHIF and private health insurance, but still ends up paying approximately KES 50,000 (US$500) per year out-of-pocket. He explained that the utility of NHIF is limited, as very few psychiatrists work in the public sector and included psychotropic medications are mostly older generation and frequently out of stock. Consequently, he also purchased private health insurance, which is still insufficient to cover all his health expenses:

> So [psychiatry] is covered by the [private] health insurance but what happens is that they would put a cap … I have a cover of maybe 3 million shillings [US$29,600], but for psychiatry they will cut - let's say you can only use it to KES 200,000 per year [US $2,000] … which of course is, in some sense, is discriminatory because then why do

> you say that I stay in the hospital and you will pay 3 million but then for certain kinds of impairments then you want to say I can only spend KES 200,000?
>
> Man with a psychosocial impairment, Kenya

A few respondents in Kenya reported successfully applying to the National Development Fund for Persons with Disabilities for assistive devices or educational assistance, which were helpful in minimising costs. Still, the vast majority of respondents did not receive assistive devices through this scheme, mainly due to lack of awareness or long wait times.

> [A] few times I have come to National Council to ask for a white cane, but you are told you have to fill out an application form and wait for it. Because I cannot move around without one, I now result to buying one.
>
> Woman with a visual impairment, Kenya

Further, repairs for assistive devices were often borne out-of-pocket. For example, a woman with a physical impairment and who is registered as having a disability and has NHIF explained that she covers the cost of repairs and adjustments for her calipers, in addition to the indirect costs of seeking care:

> It is too much for us because something very small could accumulate to around one thousand [US$10, for the repairs] … Every two months or often any time I feel something is wrong and if it is worse like today I get a taxi and the taxi man charges me a hundred shillings up to this location.
>
> Woman with a physical impairment, Kenya

No participant in Kenya or Bangladesh had benefited from the quota (10% of public sector jobs reserved for orphans and people with disabilities in Bangladesh, suspended at time of data collection; 5% of public and private sector jobs in Kenya). However, several participants in Kenya had applied for the government procurement scheme (30% reservation for people with disabilities, women and youth). Applicants were generally positive about the potential to grow their own business through this scheme, which some perceived as a better option compared to their current work. However, even successful applicants noted that their profit margins were insufficient to provide a stable source of income and the time and resource outlay applying for and fulfilling orders could be substantial.

Both settings also have disability-targeted cash transfers, although they played a more limited role in addressing disability-related costs. In Kenya, no respondents received the cash transfer due to the restrictive eligibility criteria. In Bangladesh, a quarter of participants reported receiving the Disability Allowance, however, most noted that the monthly allotment was used predominantly to meet household basic needs rather than disability-related costs.

Participants also reported challenges in accessing social protection programmes. For example, many people were not aware of the range of social protection, or faced difficulties in applying. Respondents also reported costs associated with applying for social protection programmes (e.g. travel to application offices, medical examinations). It was noted that applicants outside of Dhaka and Nairobi very likely face higher barriers to applying for and using social protection programmes due to the centralisation of services and application points.

(3)#Other Sources

A few participants indicated that employers or schools had covered some costs. For example, a woman with a visual impairment and cerebral palsy in Kenya reported that her school provided her with large-text printouts of lectures and a guide to assist her in getting to classes. Another woman with a physical impairment in Kenya was provided with taxi fare and then a loan to purchase a car by her employer. Other employers and schools provided accommodations, such as moving students with visual or hearing impairments to the front of the classroom, allowing adjusted working hours for people with psychosocial impairments or placing people with physical disabilities in ground floor offices. These accommodations helped participants stay in school or at a job, which ultimately decreased indirect disability-related costs.

Further, NGOs and DPOs were important resources. For example, some organisations provided free or subsidised assistive devices or linked participants to jobs, training courses and other opportunities that could improve earning potential. In Bangladesh, many participants had taken training courses or had been involved in livelihood development programmes run by NGOs, although not all of these were useful in improving work opportunities.

Finally, personal networks were important strategies for managing costs. These networks could either provide loans or gifts to cover expenses or connect participants with opportunities that mitigated indirect costs. Several participants reported gaining access to needed medical services, special education programmes or job placements through their networks. Conversely, the lack of social connections could be a major impediment to landing job opportunities, and participants felt certain types of jobs – particularly in government – were not open to them without connections.

Factors Affecting the Magnitude of Costs and Access to Coping Strategies

(1)#Information

Lack of information about disability, the types of disability-related goods and services required and how to access them could result in unmet direct costs and future indirect costs. For example, options for inclusive or special education were rarely known.

> … [A]fter I became deaf I didn't go to school, I stayed at home, for a couple of years and my father and mother didn't have an idea where to take me to school. But a friend of my mother explained to her that there is a school for the deaf … we went to school, and she was very surprised that there are very many deaf children there and they are using sign language.
>
> Man with a hearing impairment via sign language, Kenya

Additionally, lack of information could lead to high levels of spending on items that were ultimately not helpful. Notably, many participants in both countries reported high levels of spending on unnecessary healthcare such as frequent visits to different services providers while searching for "cures" for their disability or while trying to find appropriate providers for their health concerns. Further, some participants spent on products that were of questionable utility (e.g. poorly designed training courses, alternative medical treatments) or even potentially harmful (e.g. sedatives for people with intellectual and psychosocial impairments). For example, a man in Bangladesh reported spending his inheritance visiting different providers and undergoing different treatments for his declining vision, but none resulted in any improvements in functioning or wellbeing.

Access to information was also important for informing coping strategies. Importantly, knowledge of social protection schemes and programmes run by NGOs and DPOs could reduce out-of-pocket spending and increase work opportunities.

(2)#Delays in Covering Costs

Many participants faced delays in getting the goods and services they required or in addressing indirect costs, which could lead to higher costs in the future and limit coping strategies.

Notably, delays to seeking and receiving necessary healthcare could lead to worsening health and functioning, which then could lead to higher costs. For example, the family of a young man in Bangladesh struggled for a year to find an appropriate service provider after he developed a hearing impairment following an illness, by which point available treatment options were prohibitively expensive:

> We visited a doctor, but he said that it was too late to operate on his ear, if we had come earlier it would better for his recovery. But now it will cost more money to do any surgery in his ears. We asked the doctor about the amount of money and the doctor said, it will take about 2 or 3 lakhs [US$2,360-3,540].
>
> Brother of a young man with profound hearing impairment in Bangladesh

Additionally, challenges accessing inclusive education could lead to much higher future indirect costs from limited job options and reduced earnings.

(3)#Disability-inclusive Planning

Disabling environments caused by the lack of disability-inclusive planning led to significantly higher individual direct costs and indirect costs, and limited coping strategies. For example, limited accessible public transportation led to longer commute times, higher fares, a reliance on more expensive private transportation or geographic restriction. Similarly, the lack of disability-inclusive schools led individuals to not attend or drop out of school, pay for special schools or receive a poor quality education. Several participants also noted the low availability and centralisation of disability-related health services. Although participants were all urban-based at the time of the interview, a few had previously lived in rural areas and noted spending more to travel far distances to facilities, or not seeking services at all.

(4)#Compounding Personal Factors and Decision-Making Power

Personal factors such as age and gender affected the magnitude of costs, particularly indirect costs. For example, older adults with disabilities reported additional barriers to participating in employment due to age discrimination, while gender norms heightened exclusion from work and education for women with disabilities. For instance, one woman in Bangladesh reported "*while I was in the Master's, my family regretted [it] because people didn't want to marry me*", as the combination of having a hearing impairment and being highly educated was seen as discouraging marriage prospects. People with disabilities also did not always benefit from non-disability targeted programmes. As an older woman with a physical impairment in Kenya explained, she was excluded from livelihood programmes targeted at women or older adults because "*[t]hey first see the disability [and say] – 'this is not yours'*".

Similarly, disability combined with personal factors such as gender, age and earning potential affected power within the household – including decisions to spend on costs. Particularly in Bangladesh, women reported deferring to their husbands, fathers and other male family members for many financial decisions. For example, two women in Bangladesh were given substantial capital from an NGO to start their own businesses, but transferred ownership to male family members. One of the women explained how her son controlled the shop in their hometown while she and her daughter, who also has a disability, were living in poverty in Dhaka.

> I have given the shop to my son, I don't take any income from the shop. My son looks after that shop … he has a B.A … [my daughter and I] are sick, we don't have a male person beside us … my daughter is not getting married. She says that 'mother what will you eat if I get married? I feel very frustrated regarding this. So we the sick people sitting at home for 4 years, we are struggling more than others.
>
> Woman with a physical impairment, Bangladesh

As seen here, dowries were a competing source of costs for young women in Bangladesh, which then limits income available for disability-related costs. Some men with disabilities took in lower dowries: in one instance, the family of a man with autism, who were relatively wealthy, had sought a wife for him from a poor family (who wouldn't be able to pay a dowry) to relieve his mother of caregiving duties.

Finally, family wealth and connections were also important factors in offsetting both direct and indirect costs. Higher household income allowed for greater spending on disability-related expenses, while personal connections could reduce indirect costs (e.g. increased opportunities education, employment).

Impact of Costs

(1)#Financial Strain

Paying for direct costs led to financial strain for many participants. Some participants spent significant amounts of their income or savings, or took out loans with interest, to pay for disability-related expenses. These strategies, while necessary to cover essential items, could nonetheless push households further into poverty. For example, a woman with a hearing impairment in Kenya explained that her family had sold livestock to cover fees for a disability-targeted vocational training course. As they were already living in poverty, the loss of these productive assets meant a further reduction in the household's livelihood.

Additionally, lower and less stable earnings created difficulties managing everyday expenses. For example, a woman with a physical impairment in Bangladesh explained:

> And when I could work [before disability onset], we had a fixed amount of salary. I had a plan that I will spend 2 thousand taka for house rent, 3 thousand taka for month expenses or 1 thousand taka for savings. Like this I had a plan. But now I am struggling.
>
> Woman with a physical impairment, Bangladesh

(2)#Health and Functioning

Many participants noted how access to healthcare was critical for improving their health and functioning. For example, one man with a physical impairment in Bangladesh described how after his spinal cord injury he "*couldn't do anything … All the lower limbs were [non-functional]. I thought that I was finished …* " After six months of rehabilitation, however, he was able to walk while using a cane and his "*health is now better than before*".

Still, many participants had unmet needs for health services. Lack of timely access to needed services led to worsening health and functioning. For example, a man in Kenya became blind due to delays accessing healthcare for an ocular infection. Other participants could only afford lower quality assistive devices or older generation medications because of cost, which led to reduced functioning and side effects. For example, several participants with psychosocial impairments in both settings recalled how use of older generation drugs had led to low energy, fatigue and weight gain.

(3)#Participation

Participants emphasised the importance of direct costs such as for medication, assistive devices or accommodations for participating in school, work and social life.

Failure to meet these costs could in turn lead to decisions not to participate. For instance, a man with epilepsy in Kenya recalled how he had miss school because the drugs he was taking at the time were "*not adapting well with my body. So, I continued getting those seizures …* " Switching medication then allowed him to complete his schooling. Similarly, unmet needs for accessible transportation caused geographic restrictions and reduced opportunities for participation in work and social life for participants in both settings. In the long-term, participation restrictions caused by inability to meet direct costs could lead to higher indirect costs (e.g. unmet costs limiting schooling, which then affect work opportunities).

(4)#Wellbeing and Dignity

Some participants noted that paying for disability-related costs had negative impacts on their mental health and well-being, and strained their personal relationships. For instance, one man with a psychosocial impairment in Bangladesh had been out of work for a few years and had substantial costs for medications and psychiatry. These costs were covered by his extended family, but he shared that "*family members are getting rude because I was a burden on them. They misbehaved with me or talked so much rudely that I was totally out.*"

Further, unmet needs could cause a loss of dignity. For example, a woman with a physical impairment in Kenya explained that she needed to "*plead with people*" to assist her around her office buildings, as many areas were inaccessible. Similarly, a man with a physical impairment in Bangladesh explained that he did not have an assistive device and his household did not have an accessible toilet, and so he had to crawl on the floor to use the toilet. Additionally, several participants felt isolated or without purpose due to difficulties they faced participating. For example, a man with a hearing impairment explained how the lack of sign language interpretation led to isolation:

> When he was with other deaf persons like him, he feels good. They can talk with each other, they can understand each other. But if he has a conversation with a normal

> person, they can't understand him. He feels pain because they don't understand him, and also he can't understand the normal person.
>
> Man with a hearing impairment, Kenya (summary via sign language interpreter)

Discussion and Conclusions

Overall, this research found that people with disabilities in Kenya and Bangladesh face high direct and indirect costs. Most of these costs were borne through out-of-pocket spending, although social protection, NGOs, DPOs, employers, schools and social networks also helped manage costs. Many participants faced unmet costs or unnecessarily high spending, due to barriers such as insufficient income, poor information on items needed and how to access them, and lack of disability-inclusive planning (e.g. inaccessible built environments and information, poor availability and quality of required goods and services). Indirect and direct costs could cause financial strain, decreased health, functioning, participation and wellbeing.

The types of costs identified in this research were similar in both Bangladesh and Kenya, and reflective of those found in other settings (Palmer et al. 2015; Hanass-Hancock et al. 2017; Mitra et al. 2017). Notably, healthcare has often been identified as a large source of direct costs in both high and low income settings (Mitra, Findley, and Sambamoorthi 2009; Mitra et al. 2017), although is likely to be more impoverishing in many LMICs where health financing systems to offset individual spending are nascent. Similarly, transportation, accommodations at work and school, and indirect costs such as foregone earnings by people with disabilities and their households have been noted in other settings (Hanass-Hancock et al. 2017; Palmer et al. 2015; Mitra et al. 2017). For instance, in New Zealand, adults with visual impairments spent US$577 in extra transportation costs, although it was estimated that they required US$1822 to fully meet their travel needs (Godfrey, Jonathan, and Brunning 2009).

As with other research in LMICs (Palmer et al. 2015; Hanass-Hancock et al. 2017), this study found out-of-pocket spending was the main strategy used for managing direct costs. Social protection was identified as an important strategy by several participants in Kenya, but few in Bangladesh. Still, social protection programmes had constraints. For example, NHIF in Kenya did not cover many disability-related health services. The lack of coverage of disability-related health services and assistive devices has been noted in social health insurance schemes in other countries, such as Ghana, Iran and Vietnam (Banks et al. 2019; Government of Ghana 2019; Soltani et al. 2019) – meaning people with disabilities with health insurance may still face impoverishing healthcare spending or lack access to needed health services. Further, cash transfers and other entitlements with income thresholds or restrictions on working force people with disabilities to choose between a low, but stable source of income or opportunities that could potentially lead to higher future earnings (Mitra 2005). Losing this income, combined with additional direct costs associated with working (e.g. transportation, accommodations) may not be worthwhile given expected earnings.

Social protection and other interventions primarily address lack of income as a challenge to managing costs. This research highlighted other challenges, including lack of information, power in household decision-making and the availability and quality of needed goods and services. Further, some costs or their drivers require governmental rather than individual spending. For example, spending on improving the physically accessibility of buildings and updating school curricula and teacher training for inclusive education would be beyond the means of individuals and would require government intervention. Investment in disability-inclusive planning can offset disability-related costs: in Vietnam, people with disabilities were less likely to be poor if they lived in areas with better healthcare and infrastructure (Mont and Nguyen 2018).

This research also explored the impact of disability-related costs, including unmet direct costs – an area which has lacked research (Mitra et al. 2017). Disability-related costs could result in financial strain and decreased health, participation and wellbeing. Often, inability to meet direct costs could lead to higher direct and particularly indirect costs in the future. These findings reinforce the disability-poverty cycle, in which unmet costs (e.g. timely access to quality health and rehabilitation services) can lead to spiralling costs and greater participation restrictions, which drive the relationship between disability and poverty (Yeo and Moore 2003; Ingstad and Eide 2011). Further, this study's finding that many people with disabilities face high unmet costs due to poor availability of, lack of information about, and inability to pay for needed goods and services may explain previous observations of lower spending on direct costs in LMICs compared to high income countries (Mitra et al. 2017).

Strengths and Limitations

Some limitations should be considered when interpreting these findings. For example, this study focused on working-age adults in urban locations and therefore is not intended to reflect experiences across the lifecycle and in all settings. It is likely that sources of costs are broadly similar in rural and urban settings. However, costs for accessing healthcare and other services are likely higher in rural areas given the centralisation of many services. Similarly, coping strategies may be more limited in rural areas given typically lower incomes, access to information (e.g. due to lower literacy and education), disability-inclusive planning and reach of NGOs, DPOs and other organisations.

By age, older adults, particularly adults with later onset of disability, may experience different types of costs (e.g. none related to education or the work) and have different coping strategies for managing these costs (e.g. pensions, accrual of savings from working years). While this research did explore some costs associated with childhood (e.g. for education) amongst people with early onset of disability, additional research is needed. Further, most adults interviewed had at least a moderate degree of autonomy. Costs will be highest for adults with complex care needs, such as those requiring full-time support.

Finally, participants may differ from the wider population of people with disabilities due to the use of DPOs and NGOs for recruitment. For example, people with disabilities with some association with a DPO or NGO may have better access to information, which can minimise the magnitude of costs, or coping strategies for meeting costs (e.g. connections to social protection, programmes run through these organisations).

Still, this research presents findings from over 40 in-depth interviews with working-aged people with disabilities in two LMICs. Findings reflect a diversity of experiences, with good representation by gender and impairment type. This study contributes to the limited evidence on disability-related costs in LMICs.

Implications

Further research is needed to quantify direct and indirect costs of disability. Direct costs are particularly challenging to quantify as most commonly used methods do not capture required but unmet costs (Mitra et al. 2017). This research highlights further challenges of capturing these unmet costs, as individuals often were not aware of the goods and services they required. Research is also needed to explore the impact of interventions designed to mitigate costs: there is currently very limited evidence on the effectiveness of livelihood interventions (e.g. microfinance, job training and matching), social protection or disability-inclusive policy and planning (e.g. inclusive education, improving the accessibility, transportation, communication) amongst people with disabilities (Banks et al. 2017; Saran, White, and Kuper 2020).

This research also carries implications for policy and programmes. First, interventions to address direct and indirect costs are likely to be most effective – and cost-effective – the earlier they are provided, as unmet direct costs can lead to significantly greater direct and indirect costs in the future, while exclusion from opportunities early in life can compound exclusion throughout the life-course. Second, social protection programmes may require tailoring to improve access and impact, such as broadening the coverage of services for health insurance and removing restrictions on working from cash transfers. Further, programmes should unbundle support for extra costs from anti-poverty transfers: the amount provided by disability-targeted cash transfers in both settings ($8/month in Bangladesh and $20/month in Kenya) is insufficient to cover costs, particularly for people with high or complex support needs, as well as provide income support to households living in poverty. Finally, this study found that while social protection is an important coping strategy for managing costs, complementary programmes are needed to address other factors affecting the magnitude and ability to meet costs. In particular, disabling environments must be addressed as key drivers of costs.

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