



Knowledge, evidence
and learning for
development

Shaping Health Systems to Include People with Disabilities

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About this report

The K4D Emerging Issues report series highlights research and emerging evidence to policy-makers to help inform policies that are more resilient to the future. K4D staff researchers work with thematic experts and DFID to identify where new or emerging research can inform and influence policy.

This report is based on twelve days of desk-based research.

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Acronyms

AAAQ	Availability, Accessibility, Acceptability and Quality
COPD	Chronic Obstructive Pulmonary Disease
CBR	Community Based Rehabilitation
DALYs	Disability-Adjusted Life Years
DPO	Disabled Persons' Organisation
GDS	Global Disability Summit
HIS	Health Information Systems
ICF	International Classification of Functioning, Disability and Health
LMIC	Low and Middle-Income Countries
NSPs	National HIV and AIDS Strategic Plans
NTD	Neglected Tropical Disease
NCD	Non-Communicable Disease
PLHIV	People Living with HIV/AIDS
SDG	Sustainable Development Goal
UNCRPD	United Nations Convention on the Rights of Persons with Disability
WGQ	Washington Group Question
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization
YLD	Years Lost to Disability

DFID's vision is a world where no one is left behind. A world where all women and men, girls and boys, throughout all stages of their lives, have equal opportunities to realise their rights, achieve their potential and live in dignity, free from extreme poverty, exclusion, stigma, discrimination and violence. A world where people with disabilities have a voice, choice and control over the decisions that affect them. Where they participate in and benefit equitably from everyday life, everywhere.

DFID's Disability Framework – One Year On. *Leaving No One Behind*.

(DFID, 2015)

The first Global Summit on Disability (July 2018) focussed on the following four themes, with two cross-cutting themes on humanitarian assistance and gender:

Tackling stigma and discrimination

Inclusion in education

Routes to economic empowerment

Harnessing technology and innovation

“Unless every one of our citizens can reach their full potential our nations never will. Let today be the start of our journey. Now is the time.”

The Rt Hon Penny Mordaunt MP, Secretary of State for International Development

(DFID, 2018a)

1. Summary

The Sustainable Development Goals and the United Nations Convention on the Rights of Persons with Disabilities demands a shift in health system responses to chronic disease and disability, from the medical management and cure of disability to strengthening inclusive health systems to provide a full continuum of care that is people-centred and rights-based. People with disabilities are at a heightened risk of communicable and non-communicable diseases and these diseases can cause debility and disability. Health needs of these people often extend beyond requiring continual long-term medical support to addressing broader social inequities. Key areas that are likely to be critical in re-orientating health systems from a biomedical approach towards inclusive health systems that are more responsive to the needs of people with debility and disability in low and middle-income countries (LMICs) are offered in this report and cover the following:

1. Nothing about us without us: prioritising person-centred health systems.
2. Responding to issues of access in mainstreaming disability within health systems.
3. Ensuring the provision of specialised services.
4. Community based rehabilitation.
5. Improving the collection and use of disability related data against modified legal and policy frameworks.
6. Partnerships are paramount.
7. Financing and social protection

A responsive health system providing a continuum of care should focus on mainstreaming disability and debility within routine service provision, including at the primary level, as well as the inclusion of specialised interventions focused on supporting people with debility and disability. Collaborating with communities and persons with disability is likely to be critical in ensuring the sustainability of social and structural change to maximise inclusion.

By bringing together a body of evidence that prioritises the provision of a platform for the voices of people with chronic disease and disability, it is anticipated that this report will contribute toward DFID's "nothing about us without us" ethos, recognising that the participation of people with chronic disease and disability is essential to equitable health systems development. This report focuses specifically on evidence from LMICs. It includes evidence produced by academic research, as well as information from theoretical or conceptual research, policy papers, institutional literature and, where necessary, press releases and blogs. The provision of practical examples and case studies within the report allows for cross-contextual learning and idea generation.

There are clear links between disease, debility and disability in relation to both communicable and non-communicable disease (NCDs). Communicable diseases such as TB, HIV, malaria and many neglected tropical diseases (NTDs) can lead to debility and disability. Likewise, people with disability are often at greater risk of being affected by communicable disease due to the complex relationship between disease, disability and poverty. The large and growing burden of non-communicable disease in LMICs is also thought to contribute to approximately 80% of years lost to disability, and people with disability are thought to be at increased risk to NCDs. NCDs included in these estimates would be diseases such as Chronic Obstructive Pulmonary Disease (COPD), diabetes, cardiovascular disease, etc. Thus, debility and disability due to chronic conditions arising

from communicable and non-communicable disease requires a complex health systems response that focuses on a continuum of care. When considering disease, disability and debility it is critical to realise, however, that experiences are mediated by broader social inequities. Factors such as poverty, gender, age, conflict and fragility interact with disease and debility to shape vulnerabilities in relation to communicable and non-communicable disease in various ways, and health systems need to be able to adapt to address these vulnerabilities. Furthermore, patient experience of communicable and non-communicable disease and their associated debility and disability is unique to the individual, shaped by broader social and structural factors and frequently includes health needs that are broader than medical interventions.

Health systems need to be able to respond to provide both preventive interventions and those which focus on the case management of disease, all of which requires advances in health service delivery mechanisms and collaboration with other sectors. To date, approaches to health systems strengthening that emphasise the control or containment of communicable disease have dominated policy and programming, with limited consideration of more chronic or lifelong conditions. This has led to weak, fragile and fragmented systems in many LMIC contexts, which have also been designed and shaped by donor priorities. Consequently, the medical management or cure of disease and disability is frequently prioritised due to the dominant perspective of medical practitioners in global health policy. This leaves significant gaps in health systems to be able to deliver a solid continuum of care that allows for: prevention, detection, referral, management (including both pharmacological and psychosocial), surveillance and monitoring, and quality of care assessment, in response to the management of disease and associated debility and disability (Samb et al., 2010). Furthermore, person centred approaches that prioritise the beliefs and values of patients are frequently ignored or ill-considered. To be able to respond to debility and disability effectively within health systems, there is therefore a need to re-orientate approaches to health systems, strengthening towards a focus on multi-stakeholder and multi-sectoral partnerships that put the needs of patients and persons affected by disability at the centre of services.

2. Linkages Between Disease and Disability


Defining Health, Disability and Debility

In this section we will define how we conceptualise health, disease, disability and debility for the remainder of the report. We will also explore links between communicable and non-communicable diseases and disability, with reference to chronic lifelong disability because of disease-related debility.

Health should be explored holistically, both biomedically as an “absence of disease or infirmity” and socially, emphasising “physical, mental and social wellbeing.” Holistic exploration of health is, however, rare in public health thinking and a frequent dichotomy often exists between these approaches (Boyd, 2000). Understandings of health and wellness are often embedded in cultural belief systems and associated concepts of disease, illness and sickness are also frequently socially defined spanning both the biomedical and the social (Boyd, 2000).

As will be explored further throughout this report, disability can pose a challenge to the “absence of disease or infirmity” clause within definitions of health, as many people with chronic disease or disability still aspire to and have a right to “health” within the limitations of their condition.

Biological norms are socially constructed, and understandings and perceptions of disease frequently change by region and country (Boyd, 2000). These matter when we think about responses to disease and what may constitute “ill-health” to individuals and communities in different contexts. Ill-health is often bound up in individual and community concepts of illness and sickness, and how they are negotiated and navigated is often influenced by broader social inequities and can shape disease experience and access to health care (Barrett, 2005). As such, overemphasis on solely biomedical response or intervention in relation to disease can ignore patient experience, hindering holistic management of disease (Bury, 2001). This is particularly important in LMIC contexts where traditional health systems and understandings of disease remain prominent and can – and should – influence the design and delivery of more formal health care responses. Patient narrative also becomes particularly important when considering management and rehabilitation linked to chronic ill-health, debility and disability. Chronic disease and disability can often dominate the experience of everyday life, so unless we understand how individuals conceptualise and navigate these experiences we are unlikely to be able to respond in appropriate ways (Bury, 2001; Pluta, Ulatowska, Gawron, Sobanska, & Lojek, 2014). This becomes increasingly important in the epidemiological transition from a mainly communicable infectious disease burden to a “dual burden” of communicable and non-communicable and chronic infection in many LMIC contexts.



Debility is normally described as physical or mental weakness, particularly because of illness.


The United Nations Convention on the Rights of Persons with Disability (UNCRPD) defines **disability** as:

Persons with disabilities include 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. (UNCRPD, 2006)



Health, as defined by the World Health Organization is:

“a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1948, p. 1).



Disease, aligns most closely to biomedical approaches to health and is frequently described as a physical process that suggest deviation from biological norms (Boyd, 2000).

Similarly to definitions of health, definitions and approaches to disability often span both the biomedical and the social and, in some cases, dichotomise these components (Al Ju'Beh, 2015; Ghai, 2001; Rohwerder, 2015; TARSHI, 2018). Medical definitions or approaches to disability frequently focus on impairments, normally due to disease, injury or illness, that are seen as in need of “fixing” and pay limited attention to the social or environmental context that shapes the disabling experiences such impairments may present (Rohwerder, 2015).

Charity models of disability, like medical models, take an individualistic approach that define individuals by impairment and take a passive or pity-based approach (Al Ju'Beh, 2015). More recently, however, social constructs of disability have taken a broader societal approach, emphasising that the disabling nature of impairment is created by the society in which it is located (Mitra, 2006; Woodburn, 2013). Rights based approaches extend the social model and focus on the transformation of unjust systems through the central participation of people with disabilities (Addlakha, 2013; Al Ju'Beh, 2015; Rohwerder, 2015).

However, just as health cannot be considered a purely biomedical or social phenomenon, neither can disability. This has led most recently to a shift within programme, planning and development discourse to the use of interactional models of disability which focus on people with disabilities experiencing problems because of interactions between the environment and a health condition (Rohwerder, 2015). The most common interactional model is the international classification of functioning, disability and health (ICF). The ICF focuses on the interactions between negative health conditions and their environment or context (WHO & World Bank, 2011). This model, however, faces some critique, with suggestions that it does not fully recognise and address the discrimination experienced by persons with disabilities (Groce, Kett, Lang, & Trani, 2011). The capability approach, as a second interactional model, has been put forward as filling this gap, as it reflects in greater detail how individual characteristics, resources and environments shape individuals' capabilities to participate (Mitra, 2006).

Within this report we draw on the capability approach to disability to explore how disability can result from the intersections between personal characteristics and the environment. Due to our specific focus on the interactions between disease, disability and health, and the alignment of the ICF to the capability approach, we also draw on elements of this model due to its prominence in linking and classifying concepts of health and disability (Mitra, 2006). Both approaches allow for consideration of “actual disability” in terms of functioning or impairment, as well as “potential disability” which may indicate capability based on the interactions of impairments, activity limitations and participation restrictions (Mitra, 2006).

Disability, Debility and Communicable Diseases

Communicable diseases such as TB, HIV, malaria and many NTDs, including lymphatic filariasis, onchocerciasis, schistosomiasis, leprosy, Buruli ulcer, etc., can lead to debility and disability. Likewise, people with disability are often at greater risk of being affected by communicable disease due to the complex relationship between disease, disability and poverty.

The latest estimates of the burden of disease in terms of disability-adjusted life years (DALYs) lost due to illness and death are 58 million for HIV/AIDS, 56 million for malaria and 44 million for TB in 2016 (Global Health Data Exchange, n.d.). Chronic effects of lymphatic filariasis are described as the second leading cause of physical disability, with 40 million people thought to be affected worldwide. Despite these links, disease control efforts in relation to these diseases are frequently

implemented through vertical disease programmes that are aimed at interruption of disease transmission or “curing” infection. These approaches are important, but do not consider the fact that many communicable diseases may still cause lifelong morbidity and/or disability, even with successful treatment of the infection. This is more likely with late initiation of treatment or unsuccessful treatment. The chronicity of such morbidity can lead to a need for a more holistic response to disease and consequent disability management that considers the physical, psychological and the social implications for individuals, households and communities. This requires consideration of the chronicity of these conditions in health systems, strengthening efforts and demand for the development of more “horizontal” health interventions.

Box One: Communicable Disease, Debility and Disability: Examining Links and Health Systems Responses Through the Example of HIV

The disabling experience of HIV has been well-documented. However, it is only more recently that attention was given to the fact that HIV and AIDS affects people with disabilities (Hanass-Hancock & Nixon, 2009) and that people with physical, mental, intellectual or sensory disabilities are a key population at higher risk of exposure to HIV (UNAIDS, 2009). Higher prevalence rates in persons with disabilities compared to the general population have been shown in South Africa (Shisana et al., 2009, as cited in Grant, Strode, & Hanass-Hancock, 2009, p. 8), Kenya (Taegtmeyer et al., 2009, as cited in Grant et al., 2009, p. 8) and Cameroon (Touko, 2009, as cited in Grant et al., 2009, p. 8). Factors associated with people with disabilities – including higher levels of illiteracy, unemployment and poverty, and risk of sexual abuse and assault – increase the vulnerability of them becoming infected with HIV and the HIV infection having a greater impact (Elliott, Utyasheva, & Zack, 2009 and Groce, 2004, as cited in Grant et al., 2009, p. 8). Health systems should provide for disabilities that may develop as a result of HIV, such as mental health problems, physical disabilities, deafness or blindness (through providing devices for assistance), rehabilitation, psychosocial support and disability grants (Hanass-Hancock, Strode, & Grant, 2011). Health systems also need to provide services for episodic disabilities in ART patients (Hanass-Hancock & Nixon, 2010).

A study analysed the extent to which National HIV and AIDS Strategic Plans (NSPs) integrate and address the specific needs of people with disabilities as a population vulnerable to HIV and AIDS, as well as the needs of people living with HIV/AIDS (PLHIV) who may become disabled (permanently or episodic) because of HIV and AIDS in 18 countries in Eastern and Southern Africa. The findings of the report show varied country responses, with less than 50% of countries specifically recognising disability due to HIV and AIDS within their NSPs. Even where countries have recognised disability, there is limited specific guidance on HIV-related service provision to meet the needs of people with disabilities (Hanass-Hancock et al., 2011). Only South Africa showed extensive integration of disability into its NSP (Hannass-Hancock et al., 2011). This report provides recommendations to enable policy and law makers to address disability in NSPs, and to enable civil society to lobby for strengthening integration of disability within the national response to HIV and AIDS (Hannass-Hancock et al., 2011).

Disability, Debility and Non-Communicable Diseases

LMICs have a large and growing NCD burden (Richards et al., 2016) exacerbated by ageing populations (Kampfen, Wijemunige, & Evangelista, 2018). NCDs, including diabetes, cardiovascular disease and chronic lung health conditions such as COPD, are thought to contribute to approximately 80% of years lost to disability, and people with disability are thought to be at increased risk to NCDs (Richards et al., 2016).

NCDs can lead to impairments related to amputations, blindness, mobility and speech. Such impairments can reduce productivity, increase demand on the social and health systems and impoverish families due to associated activity and participation restrictions. It is estimated that between 2008 and 2030, diabetes, cardiovascular diseases, cancer, chronic respiratory diseases and mental illnesses will cost LMICs US\$21 trillion due to illness and lost production (Kruk, Nigenda, & Knaul, 2015).

Information on the prevalence of NCD-related disability and corresponding rehabilitation is scarce (Richards et al., 2016). For many LMICs, the Global Burden of Disease study estimates of disability-adjusted life years (DALYs) and years lost to disability (YLDs) are all that is available. The latest 2016 estimates of the burden of disease in terms of DALYs lost due to illness and death are 57 million for diabetes, 353 million for cardiovascular diseases and 163 million for mental disorders¹. Seventy percent of people with diabetes live in LMICs (Richards et al., 2016). The primary goals of NCD care – to enhance functional status, minimise symptoms and prolong and enhance quality of life, rather than to cure – are not captured in current health information systems (Richards et al., 2016). Local valid data on rates of NCD-related disability, statistics on functional status, rehabilitation needs, and the coverage and utilisation of relevant health services are required to measure disease burden, evaluate the effectiveness of health interventions and build the evidence required to guide policy responses (Richards et al., 2016). Richards et al. (2016) argue for the need to improve health data by: incorporating measures of NCD-related disability into discussion on NCD prevention and control; strengthening information systems to better capture data on disability; and aligning NCD and disability measurement and monitoring strategies. They also argue for the chronic disabling states caused by NCDs to be recognised and incorporated in all global action and monitoring frameworks on NCD prevention, control and treatment.

The link between communicable diseases and chronic ill-health or NCDs also needs to be considered in health systems responses to disease, debility and disability. This is particularly important in relation to mental health conditions, which are anticipated to be the largest contributor to the global health burden by 2030 (Litt, Baker, & Molyneux, 2012). A review by Litt et al. (2012) suggest that factors associated with NTDs predispose individuals to poor mental health. These include stigma and discrimination, exclusion from participating fully in society, reduced access to health and social services, lack of educational opportunities, exclusion from income-generation and employment opportunities, and restrictions in exercising civil and political rights – especially for those with physical disability and permanent disfigurement (Litt, Baker, & Molyneux, 2012). For example, lower quality of life scores were associated with mental illness in patients with podoconiosis in northern Ethiopia (Mousley, Deribe, Tamiru, & Davey, 2013). Effects of chronic ill-health and disease are frequently not limited to the affected individual and this is particularly the case for NTDs. However, research is lacking on the impact of NTDs on the mental health of caregivers (Litt et al., 2012).

¹ <http://ghdx.healthdata.org/gbd-results-tool>, accessed 30 October 2018

Health systems therefore have a dual role in the management and treatment of both communicable and non-communicable disease. They need to be able to:

1. Address the needs and rights of people with disabilities as a population group at heightened risk of communicable and non-communicable disease as well as at risk of exclusion from services.
2. Address communicable and non-communicable diseases as leading causes of disability.

3. Political Prioritisation of Inclusion

The Sustainable Development Goals

Over a billion people globally are estimated to have a disability (WHO & World Bank, 2011). Including a disability perspective in discussions on communicable and NCD prevention, control, treatment and measurement is in line with Sustainable Development Goal (SDG) 3, to ensure healthy lives and wellbeing. Disability is referenced in various parts of the SDGs and specifically under five of the seventeen goals – goal 4 guaranteeing equal and accessible education by building inclusive learning environments and providing the needed assistance for persons with disabilities (PWDs); goal 8 promoting inclusive economic growth, full and productive employment allowing PWDs to fully access the job market; goal 10 emphasising the social, economic and political inclusion of PWDs; goal 11 creating accessible cities and water resources, affordable, accessible and sustainable transport systems, providing universal access to safe, inclusive, accessible and green public spaces; and goal 17 underlining the importance of data collection and monitoring of the SDGs, emphasis on disability disaggregated data². As well as specific references within the SDGs to disability, the underlying principle of the SDGs of “leaving no one behind” emphasises the inclusivity of all the goals, ultimately rendering them relevant and disability mainstreaming critical in their attainment.

The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (OP) was adopted on 13 December 2006 at the United Nations Headquarters in New York and entered into force on 3 May 2008. The CRPD has been the most rapidly ratified international treaty - as of 11 November 2016, 116 States and the EU ratified the Convention, representing 87% of Member States in the United Nations. The World Health Organization (WHO) and World Bank Group subsequently jointly produced the World Report on Disability in 2011 to provide the evidence for innovative policies and programmes that can improve the lives of people with disabilities and facilitate the implementation of the CRPDs (WHO & World Bank, 2011). People with disabilities, as defined in the Convention, are those who have long-term physical, mental, intellectual or sensory impairments which hinder their full and effective participation in society on an equal basis with others. A flagship report on disability and development is due to be published in 2018 reflecting progress made in addressing the relevant internationally agreed development goals and the provisions of the CRPDs. Health and wellbeing is expected to be considered in this report. The

² SDGs and Disability: <https://www.un.org/development/desa/disabilities/about-us/sustainable-development-goals-sdgs-and-disability.html>

CRPD emphasises the right to health and rehabilitation with two specific requirements of ratified states:

- To ensure that persons with disabilities are reasonably accommodated in the context of health care services, and
- To ensure accessibility more generally to health care services.

Global Disability Summit

On 24 July 2018, the UK government co-hosted the first ever Global Disability Summit (GDS) with the International Disability Alliance and the Government of Kenya. The summit took place in London and brought together approximately 1,200 delegates from governments, donors, multilateral agencies, private sector organisations, charities and organisations of persons with disabilities. The summit was a call for global action.

Ambitious new global and national level commitments on disability inclusion were made that, if turned into action, will create lasting change for PWDs around the world (Global Disability Summit, 2018a). One hundred and seventy sets of commitments were made around the four central themes of the summit – ensuring dignity and respect for all, inclusive education, routes to economic empowerment, and harnessing technology and innovation with two cross-cutting themes on humanitarian assistance and gender. The principal legacy document of the GDS was the Charter for Change (Global Disability Summit, 2018b) – an action plan to implement the UN CRPDs to which over 320 organisations and governments signed up to. Following the summit, DFID and co-hosts have developed an accountability mechanism to support and monitor progress made against the GDS commitments and a one-year-on progress report will be produced to share good practice and lessons learnt³. An online portal is also being created on the International Disability Alliance website to ensure all commitments are highly visible and accessible⁴.

Many governments and policymakers do not know how many people in their countries have disabilities, which means that they also do not know how to make sure PWDs are included in the life of their communities and can access services. A lack of accurate data on disability affects the way decision-makers plan, budget, allocate resources and influence policies. Data can be gathered using the Washington Group Questions (WGQs). Rather than asking people if they have a disability, these questions ask whether people have difficulty performing everyday tasks such as walking, seeing, hearing, communicating or getting dressed. This can help to identify people with disabilities even though they may not classify themselves as “disabled.” Over 300 organisations made the commitment to use the WGQs in surveys and censuses at the GDS.

DFID’s first ever Disability Inclusion Strategy was published in December 2018 and sets out how the organisation will deliver its vision: “where all people with disabilities, women, men, girls and boys, in all stages of their lives, are engaged, empowered and able to exercise and enjoy their rights on an equal basis with others, contributing to poverty reduction, peace and stability” (DFID, 2018b). It prioritises four strategic pillars for action: (i) inclusive education, (ii) social protection, (iii) economic empowerment, and (iv) humanitarian action. It sets out three additional cross-cutting areas, vital to disability inclusion, which will be consistently and systematically addressed: (v) tackling stigma and discrimination; (vi) empowering girls and women with disabilities; and (vii) access to appropriate assistive technology. And it includes new ambitions on mental health.

³ GDS - final summary: <https://www.gov.uk/government/publications/global-disability-summit-final-summary>

⁴ IDA Portal: <http://www.internationaldisabilityalliance.org/summit>

4. Health Systems Reach

Why Intersectionality is Important in Considering Disease, Debility and Disability

Intersectionality is an epistemological standpoint that seeks to:

move beyond single or typically favoured categories of analysis (e.g. sex, gender, race and class) to consider simultaneous interactions between different aspects of social identity as well as the impact of systems and processes of oppression and domination. (Hankivsky & Cormier, 2009, p. 3)

It provides a platform to conduct multi-layered analysis that considers how experiences of privilege and penalty, and their underlying drivers, may interact and alternate between and within contexts due to multiple intersecting axes of power (Hankivsky, 2012). Intersectionality is important when considering disease and disability, as experiences of both are mediated by broader social inequities such as age, class, race and gender. In the following sub-sections, we explore how disease and disability intersect with other axes of social disadvantage to shape individual experience and outcome. Where possible we draw on case studies from people affected by disease and disability to illustrate these concepts and theories.

Poverty

Poverty and disability are commonly discussed as having a mutually reinforcing relationship. Poverty is thought to increase the likelihood of disability due to enhanced risk of stress and social exclusion, lack of access to healthcare, inadequate water and sanitation, malnutrition and poor living conditions, all of which can lead to poor physical and mental health that can become disabling. Simultaneously, disability often leads to exclusion from work, education and healthcare which can in turn result in, or deepen, poverty. Poverty associated with disability is also thought to be exacerbated by environmental factors, gender, age, type of disability, and economic context of the individual or family prior to impairment (DFID, 2000; Rohwerder, 2015). Despite these commonly described associations, the evidence base for the links between the broader dimensions of poverty (including social exclusion, dignity, respect, employment, knowledge/information, etc.) and disability is thin, specifically when considering empirical evidence that may be used to inform the design and delivery of policy and programmes. This is perhaps due to complicated definitions of poverty and disability, but highlights a clear evidence gap in ensuring progress toward the attainment of the SDGs and ensuring that no one is left behind (Banks, Kuper, & Polak, 2017; Groce et al., 2011).

Economic poverty associated with disability is thought to have implications at the individual and household level, and can result from: direct costs associated with having to pay for increased medical and travel costs; indirect costs due to family or community members acting as caregivers for people with disability; and opportunity costs because of lost income or productive work of key members within the household (Rohwerder, 2015). A recent systematic review indicates strong evidence for the links between disability and economic poverty, which remains true when adjusted for confounders including age and gender. This relationship was described as increasing with levels of poverty and severity of disability. Disparities between those who are poor and those who are less poor was shown to be greater in areas where wealth was generally higher, suggesting that inequities develop over time – however, understanding which factor comes first (disability or economic poverty) is still challenging (Banks et al., 2017b). Amongst the studies reviewed in

Banks' work, where associations were not found between economic poverty and disability, other layers of analysis highlighted associations between disability and other indicators of poverty, such as educational level or employment status. As described above, this emphasises the need for studies that explore links between poverty and disability using multi-dimensional approaches. Cumulative exposure to poverty, where many adults have been exposed to adverse economic and health environments, and the co-existence of communicable and NCD burdens in resource-constrained health systems, is challenging to respond to in LMICs (Kampfen et al., 2018).

Gender

Gender is a power relation based on socially constructed differences of roles and expectations between men, women and people of other genders (Ghosh, 2013). Disability is also a power relationship between people with activity limitation or impairment and those who are not; this power relation frequently devalues and excludes people with disability from society through their construction as deviant (Ghosh, 2013). Thus, both gender and disability are binary constructions with privilege on one side of the binary. Such binary distinctions, however, poorly represent the fluid realities of people's lives. Gender, disability and other social constructs such as age, sexuality, race and class all intersect and mutually construct in various ways to mediate experiences and lives of people with disabilities.

The specific intersection between gender and disability in many LMIC settings significantly shapes disease experience, with vulnerabilities and discrimination being centred on the ability to fulfil stereotypical or socially assigned gendered roles, such as those of men as economic providers and women as responsible for reproductive work, including caregiving. For many women with disability, marriage prospects are seen to diminish due to stigmatisation linked to disease and disability. In addition, where women are already married prior to their disability they are often vulnerable to divorce, or in the case of polygamous households, their position and power within the household weakens (Allotey & Gyapong, 2005). Caregiving responsibilities for people with disabilities also frequently have the most impact on women due to their ascribed gender roles (Zuurmond et al., 2016). Misconceptions can leave many women with disabilities unable to attain their sexual and reproductive rights as they are characterised as having no sexual needs, desires or agency (Dean, Tolhurst, Khana, & Jehan, 2017). Box Two, presents a case study from Sudan that shows how gender, disease and debility, in this case in relation to asthma, can contribute to diminished marriage prospects and social exclusion. Men with disability are more likely to be perceived as entitled to a sexual life due to the intersection of disability and patriarchy (Addlakha, 2007). However, for many men with disability, feeling or being unable to fulfil a role as an economic provider within the household can be "emasculating" and have negative connotations for men's mental health and wellbeing.

Box Two: Disease, Debility, Disability and Gender: A Case Study of Asthma and Marriage in Sudan (Mr Hafiz Hussein, linked to the IMPALA Project).

Randa is an unmarried 26-year-old female university graduate. Randa was diagnosed with asthma in secondary school and she was prescribed with an inhaler to relieve asthma symptoms. Randa's mother insisted that she should not use the inhaler publicly as girls who use inhalers have reduced chances of getting married. Local perceptions suggest that women living with asthma are not able to fulfil their ascribed role as a wife in the community as they are unable to complete tasks such as cooking, cleaning and other domestic work. Randa described that

since that time I have obeyed my mother and never used the inhaler in front of anybody - even my closest family members. When I am having attacks all I say to people at that moment, all I say, is that I have allergy, because allergy to some extent is more acceptable than asthma, especially for unmarried women.

Randa continued her story, narrating that

when [she] joined the university, things had changed, and [she] gained new knowledge regarding respiratory diseases and became a member in an association that was advocating for health rights and reducing stigma. Through the association, [she] has advocated for asthma and other respiratory diseases. [She] found herself using an inhaler in public despite [her] mother's alert. [In 2016, Randa entered a relationship with a] good guy and one day while [they] were discussing and arranging for the wedding day, [she] used the inhaler and took two puffs in front of him, he was shocked and asked in astonishment: "Are you asthmatic?" Randa replied: "Yes, I am."

Randa described continuing the discussion with her boyfriend, but that there was a different mood, especially from his side. She described how things between them deteriorated and lastly, they did not marry. Randa felt that this was most probably because *"he discovered my disease and I am not up to his expectation in marriage."* In Randa's story we can see how gender and debility or disability in relation to asthma intersect to shape her experience and ultimately lead to a lost opportunity for marriage. In a Sudanese context, being unmarried can be highly stigmatising and can lead to further social isolation. Nevertheless, Randa's determination to use her inhaler in public despite the impacts to herself present opportunities to work with people affected by chronic disease and disability to promote social change.

There is also evidence that women, men, boys and girls with disabilities face increased rates of violence, including gender-based and disability-violence, which may intersect (Fulu et al 2014). Both gender- and disability-based violence stem from power imbalances between genders and people with or without disability (Fulu et al 2014). Disability-based violence tends to originate in contexts where people with disabilities are not viewed as people deserving of equal rights (Fulu et al 2014). Gender- and disability-based violence can be physical, psychological or economic, and although both men and women can experience violence of this nature, evidence suggests that, worldwide, women are more likely to experience violence and more severe violence, and for longer time periods (Fulu et al 2014). Higher levels of violence amongst people with disabilities, particularly women, are thought to be influenced by broader social structures, including patriarchal attitudes and social structures, relative lack of power, and limited access to services.

Women and girls with disabilities are at three times greater risk of rape by a stranger or acquaintance than their non-disabled peers, according to existing evidence (Andrae, n.d.; Ghai, 2001). These risks are exacerbated when poor sanitation infrastructure means women and girls must defecate openly; or when travelling long distances to school or work. This highlights a clear intersection of how gender and community-level poverty can intersect to produce vulnerability. Women and girls can be at risk in these environments due to a social and infrastructural environment that not only makes them easy targets to dangers such as sexual violence, but also presents challenges in communicating or reporting incidents of violence. There may also be risks of violence, including sexual violence, for men and boys with disabilities, particularly in conflict settings; however, these are even less documented and due to increased social stigma attributed to men who experience such events, reporting of incidents of sexual violence is even less likely. Barriers also exist to supporting men and women who have experienced either gender or disability-based violence; for example, in Northern Uganda many women described having to pay fees to register incidences of sexual violence (Andrae, n.d.). Thus, in the Uganda case, gender and poverty can intersect to compound vulnerabilities. Women with disabilities also often experience psychological violence, which can include wilful neglect, persistent insults, and in some cases isolation or detainment. Such experiences throughout the life course can contribute to the invisibility of disabled women, resulting in negative mental health outcomes.

Box Three: Anjali's Story - Intimate Partner Violence and Disability in Gujarat, India

Exert taken from Dean et al. (2017).

Anjali's story demonstrates how her lack of autonomy in her natal family, and violent and controlling behaviour by her husband, interacted and reinforced each other, limiting her access to both mobility and medical care and creating feelings of isolation, vulnerability, despair, and suicidal ideation.

Anjali is 24 years old, mobility disabled and moves around her home by dragging herself. She was married despite "telling them [her parents] I will get better offers [if she waited] as my age was hardly 13–14 years." Her parents felt that, "your legs are like this, you won't find anyone else' . . . and didn't pay any need to my requests." As a result, she said, "my soul [was] forced to get married." Once married, Anjali sought access to treatment for fertility problems with the permission of her husband. At a later stage, however, her husband "stopped the treatment" and when she asked him why, "he won't give a proper answer. [. . .] Now he beats me [. . .] and has dismantled my tricycle and told me that I should not go here nor there." As a result, Anjali has been left to feel "I should consume medicines and go off to sleep. Then, at times, I feel like burning myself to die. . ."

Isolation and detainment can also extend to the denial of access to healthcare, education and financial resources, all of which are often entangled with forms of economic violence and reduce the autonomy and participation of women with disabilities in decision-making processes. The evidence base on how to prevent and respond to violence in relation to people with disability is limited (Mikton, Maguire, & Shakespeare, 2014). There is some indication that increasing the economic independence of women with disabilities is likely to decrease the risk of gender-based violence, however more work is needed in this area (Fulu et al 2014).

Children

The number of children with a disability worldwide is thought to range between 93 million and 150 million. Most of these children are thought to live in LMICs and approximately 13 million are thought to experience “severe difficulties” (Kuper et al., 2014). Despite these estimates, data on childhood disability is scarce and of poor quality (Kuper et al., 2014). Childhood disability is thought to impact both children and their families’ social and economic participation in many ways. Children with disability frequently do not start school, and the number of children with disability attending school decreases through school transition. Disability and poverty also intersect to reduce the likelihood of going to school, and in many cases, girls with disability may be less likely to enrol in school than their male counterparts. The gap between attendance rates of children with disability compared to their peers is most disparate at secondary school level (Kuper et al., 2014).

Exclusion from education disadvantages children and their families for their entire life-course, with significant negative implications on wellbeing due to increased isolation and vulnerability and enhanced dependence on a network of caregivers (Banks, Kelly, Kyegombe, Kuper, & Devries, 2017; Kuper et al., 2014). Children, particularly girls, who are caregivers of parents with disability are also much less likely to go to school, emphasising the generational impacts of disability (Kuper et al., 2014). Greater caregiving responsibilities on families, both due to a lack of inclusion of children with disabilities in education systems, as well as more generally, can lead to exclusion from economic productivity (Zuurmond et al., 2016). A study in Uganda and Malawi highlighted that this can be exacerbated within one parent families, where a reduced number of economic providers frequently requires a trade-off between enhanced caregiving needs of the child and livelihood activities (Zuurmond et al., 2016).

Box Four: Hannah’s Story: Adolescent Disability and Household Impacts

Case Study from Ms Laura Dean’s PhD Study: Understanding Illness Experience of NTDs Endemic to Liberia: Opportunities and Threats for Integrated Disease Management, Disability and Inclusion Strategies.

In 1989, Hannah was happily attending school and her family were told “*to take care of her because she was clever.*” Hannah wanted to be a doctor. In 1991, as a teenager, Hannah started to experience severe itching on her skin and “tears were coming from her eyes” when she looked at the light. Liberia was in conflict and health seeking was difficult. Hannah’s mother sought care for her daughter in Guinea and the Ivory Coast where she accessed traditional medicines, before finally reaching a hospital in Liberia where she was given Filaria medicine. She was told to return to the facility when the medicine ran out, but healthcare seeking was expensive. The family asked for support from the community to return to the hospital but people did not have money; it was the end of the war, and they were frequently told “*the way we come from war that who got money, our money then we are keeping it oh.*” In 1994, Hannah described that she woke up “*noticed that she couldn’t see her parents again, she started telling them I can’t see, I can’t see, [I] was looking all around for things from beside [me], [I] was looking for something to just finish [my] life.*”

Since 1994, Hannah described that *“men will come and tell me they will help me, but after a period of time, they leave”*, she explained that she has given birth to four children but she has sent them to her sister as she and her mother struggle for food and *“when they [her children] be here [and] she gets food, [then] she gets nothing, so that the reason why she asked her sister so at least she can take some [food] for them.”* Contribution to the household is difficult for Hannah, and her siblings often exclude her and tell her that they have their own children to look after, *“they don’t want to be close [to her], they just distance themselves [from her].”* As a result, Hannah’s mother has become her primary carer. Hannah felt herself to be a liability or burden on her mother and was worried *“who will take care of me, when my mother dies”*. Hannah described that the recent medicine they brought for Filaria she took, and this helped her skin to stop itching, however, she still struggles to move around in the community due to her eyes as she feels *“afraid”* and *“ashamed”* and *“people might laugh at her”*. Her toilet is outside and far from the house, so she must defecate just behind the house so as not to move too far. The place where she can retrieve clean water is also too far for her to access. Despite facing numerous challenges, Hannah described listening to the *“radio to find comfort”* and a desire to be able to *“make and sell clothes at the market”* to support her and her mother.

Hannah’s mother described that since her daughter had got sick she had given up farm work and her job as a trained traditional midwife to *“just sit down and look after her daughter”*. As a practising Catholic since her daughter’s sickness *“decided to be praying in the house with her. [I] can’t go there [to church] to leave her... [I] can’t go nowhere to leave her...for that reason [I] just decided to be glue to her.”* When asked why, she explained: *“because Hannah always saying she will kill herself. So, [I am] afraid maybe if [I] go out, she may come and take something to harm herself. So, for that reason [I] don’t want to go far from her.”* She described that they have been living like that for a long time now and have received no help. She worries about what will happen to her daughter when she is not around. She also described conversations with her daughter where her daughter considers killing herself to reduce the burden on her mother. She described that because of the situation, her and her daughter often struggle for food, and they are reliant on donations from people in the community. She described that sometimes people will give them money which they use to buy some cups of rice that they save for when they are hungry. She described a division in the household between her children, stating that on good days her other children would share with her and her daughter but on bad days they do not.

Hannah’s story highlights the impact that disability, because of onchocerciasis, can have on both an individual and on other members of the household, in ways that are influenced by gendered roles and poverty. The impact on Hannah, her mother and children, presents a need for holistic support interventions for people who are living with the clinical manifestations of onchocerciasis, such as skin disease and blindness, to ensure their psychological, social and physical support needs are met. It is only if these things are provided that we will ensure that no-one is left behind in managing the impacts of onchocerciasis. Programmes or interventions should consider how to enhance collaboration with the primary health care system as well as the disability community, to ensure that the needs of these individuals are not forgotten as we move toward onchocerciasis elimination.

Children with disabilities are also thought to face a higher risk of violence than their peers (Banks et al., 2017a). A study in high income countries suggested that the risk of violence was 3-4 times greater amongst this group. There is, however, a paucity of evidence relating to children with disability and violence in LMIC contexts. Consequently, services and protection mechanisms for children with disability at risk of or experiencing violence are underdeveloped (Banks et al., 2017a). Furthermore, where child protection strategies may exist in LMIC settings these are infrequently adapted to meet the specific needs of children with disability: for example, they are not inclusive of alternative communication needs (Banks et al., 2017a). There is need for further research into disability-related violence in children that documents both the experiences of children with disabilities as well as that which quantifies the issue.

In relation to accessing health care services, evidence indicates that children with disabilities not only have worse access, but also higher healthcare needs (Kuper et al., 2014). Children with disabilities in LMIC settings are thought to be at increased risk of serious illness and malnutrition (Yousafzai, Filteau, & Wirz, 2003), both of which can exacerbate disability further (Yousafzai et al., 2003). Despite these known risks, there is limited understanding of the links between disability, disease and illness amongst children in LMIC settings. Unless these are better understood, it is highly unlikely that we will be able to meet the health needs of children in these settings (Kuper et al., 2014; Yousafzai et al., 2003). A focus on the health and education of children with disabilities within development agendas is essential to ensure their social participation and prosperity for the future (Kuper et al., 2014). Twin track approaches that focus on the mainstreaming of children with disability within existing health and education interventions are likely to be essential, alongside those that are tailored and specific to unique and individual support needs (Kuper et al., 2014).

Finally, children with disabilities, particularly those with intellectual disability, are at high risk of being institutionalised or detained in many LMICs. As highlighted by the Méndez report, there are alternatives to detention such as care and guidance (Méndez, 2013). Unfortunately, in many contexts around the globe, detention or institutionalisation is a go-to resort in many cases. There is a need to develop strategies that respond to institutionalisation as a primary option and ensure that this is only used as a last resort. Furthermore, where detention is a last resort, this should take place for as minimal amount of time as possible, with appropriate safeguarding in place and in the least restrictive ways possible. Adoption of policies, legal frameworks and practices that enable children to remain de-institutionalised is an essential step forwards in maximising inclusion of people with disabilities. Health systems can support de-institutionalisation by designing treatment strategies that provide short term in-patient care when required, which are accompanied by longer term out-patient community-based treatment strategies. Community based rehabilitation strategies discussed in the latter sections of this report provide a good platform for this type of care. This will also rely on strong capacity strengthening efforts regarding the inclusion of persons with disabilities at the primary care level, as this is often the key point of contact of these individuals with the health system (Rosenthal, 2017).

Conflict and Fragility

Conflict and fragility, including episodes of disease outbreak (e.g. Ebola) or natural disaster (e.g. earthquake), can present people with disability with enhanced vulnerabilities. During these periods, social support services including those related to health, education or income may be unavailable or inaccessible. For example, during the recent Ebola outbreak in West Africa, many people with disabilities were unable to understand or engage with health communication messaging as it was ill-adapted for their needs, and as a result they were further marginalised and placed at increased risk of infection and associated psychological trauma. In times of war, this can also be the case, particularly for people with sensory impairment, who may find it difficult to interpret what's going on, as well as when and where to flee from danger. In humanitarian settings, caregivers of persons with disability, particularly parents of children with disability, can face a magnification of vulnerabilities due to challenging environmental, social and cultural factors that result in their exclusion and limited access to services, which is heightened during periods of service scarcity (Zuurmond et al., 2016). For example, children with disability may be more likely to be malnourished in conflict settings but have worse access to feeding programmes (Zuurmond et al., 2016). Having said this, in some conflict affected or fragile settings which have been reached by humanitarian assistance, there can be increased access to services and resources which can be of benefit to people with disabilities – for example, provision of water and sanitation services. Accompanying education programmes can also frequently support in transforming community opinions and perceptions surrounding disability. Conflict and fragility can also cause significant demographic shifts and lead to increases in prevalence of disability due to disease, injury and enhanced psychosocial support needs. For example, as is the case in Jon's story in Box Five, weaknesses in health systems during periods of conflict that can lead to inability to access care for communicable disease, can result in debility and disability and unmet health and social care needs for individuals, households and communities.

Box Five: Conflict, Fragility, Communicable Disease and Disability: An Example from Liberia

Case Study from Ms Laura Dean's PhD Study: Understanding Illness Experience of NTDs Endemic to Liberia: Opportunities and Threats for Integrated Disease Management, Disability and Inclusion Strategies.

Jon is 46 years old and lives in a peri-urban village in Liberia. Since 1991 Jon had been running a Methodist school in his community. Jon established the school during Liberia's conflict so that the children of the community could be educated as there was no government school at that time. On a wall in Jon's house, he had documented his story in chalk. Each marking means something to him as a step on his pathway to today. The below gives a brief overview of Jon's story, culminating in how he currently feels because of being blind due to onchocerciasis.

In 1985, Jon had experienced severe itching and sought treatment at the hospital, where he was given Banocide. He describes "*They 'cut my skin' at that time and told me it was filaria, they said it was inside plenty, [the medicine] worked my skin could not itch again.*" However, in 1990, the itching started again. This was during Liberia's conflict, so accessing medicines for Jon was challenging. Despite believing that he had been "infected" by someone in his community following a disagreement, in 2005 Jon began healthcare seeking for his illness. Firstly, he went to the hospital, where they told him there was nothing they could do. Jon then went to see an old lady in the community who gave him bitter root to manage the itching. In 2012, he went to a larger hospital where he was told he had glaucoma and then cataracts, which needed surgery.

He was given medicines to reduce his blood pressure – however, the medicines didn't work, so the surgery never took place. The costs of healthcare-seeking, and medicines, were very high so Jon returned to his community. When the mectizan distribution programme then came to his community, some of the distributors were charging for the medicine, but Jon went to the distributor's house and demanded the medicine. He still couldn't see "the wall" right, so he decided to go back to the hospital. He was told it was filaria and given some more medicines. Despite describing that "even when I took that medicine now my whole body [am] starting scratching" and consistent care-seeking, Jon's sight was deteriorating. He described that word had spread in the community that he was going blind, until the last entry on the wall, where he told us: "I feel hurt when I open it [his eyes] I can see no writing. Hmm I can see no writing."

Since this last entry, Jon described how his wife had left him and taken their children to live in another community, due to the criticism and pressure she had faced in that community because of his blindness. Jon described how challenging he found it being alone in the house, as he couldn't fix the leaking roof and often slept on the wet ground; he also described challenges in finding food. When asked what he does each day, he described "I just sit down the whole day. You alone and you know what it means."

Jon described his last chalk marking and going blind as the end of his journey, as he now felt isolated and alone. Jon no longer teaches in the school, which he explained affects him and the community. As we move toward onchocerciasis elimination in many contexts, it is vital that people like Jon are not left behind and that this isn't the end of their story. Identifying ways to support people living with visual impairment and their families is a critical part of achieving health for all and equitable onchocerciasis elimination, and should not be forgotten. Furthermore, in contexts such as Liberia that have faced challenges in implementing continuous mass drug administration campaigns due to periods of instability and conflict, additional efforts should be made to strengthen health systems so that when people like Jon seek help, it is readily available to them.

Box Six: Rebuilding a Health System Post Conflict: Using Life and Job Histories in Northern Uganda to Explore Priorities and Respond to Mental Health Challenges

Synthesis of information from Ssali and Theobald (2016), linked to the [REBUILD project](#).

This case study considers the recommendations from a study that used life and job histories to explore experience of conflict in Northern Uganda. The evidence presented here is in specific relation to mental health and the importance of its consideration in re-building health systems in post conflict settings. The following quote is one excerpt from the paper that emphasises the critical importance of mental health in post-conflict settings:

... I lost my children during the LRA insurgency, two of them died during the insurgency and they were already big boys. In 1990, I fell ill only once but it was a very serious illness. ... We had to run and we were in the camp in Bungatira Coopee and I was brought to the government hospital in town where I recovered and that was the last time I fell seriously ill. I do not know the year ... The Karimojong took my cattle. By then, my children were already fully grown up ... It must have been 1991 ... I am still suffering from it up to now. (87-year-old man)

From their analysis of multiple life and job histories Ssali and Theobald (2016) make several recommendations for consideration when rebuilding a health system in post-conflict settings to ensure responsiveness to mental health:

- There is a need to think about systems hardware and software. Post war reconstruction frequently focuses on the hardware of the health system e.g. building clinics. However, particularly when considering mental health challenges and psychosocial disability because of war there is a key need to also focus on the software of the health system to respond to how people experienced and describe their own suffering linked to conflict. This may mean a need for preventive and curative services within communities and health centres to promote community healing.
- Service allocation should not only focus on the immediate causes of disease and mortality such as maternal health care or HIV programming but should prioritise managing the distress that conflict can induce through specific attention to develop strong mental health service delivery platforms.
- Health systems need to respond to gendered care needs, for example, women's needs are often prioritised as a result of conflict however it is important to also recognise men's care needs both physical and psychosocial. This can contribute toward ending perpetuating cycles of violence linked to defending masculinities.

5. Health System Responses to Disease, Debility and Disability

Through the case studies and discussion in the previous sections we have emphasised that:

- Debility and disability due to chronic conditions arising from communicable and non-communicable disease require a complex health systems response that focuses on a continuum of care.
- Debility and disability can shape vulnerabilities in relation to communicable and non-communicable disease in various ways, and health systems need to be able to adapt to address these vulnerabilities.
- Patient experience of communicable and non-communicable disease and their associated debility and disability is unique to the individual, shaped by broader social and structural factors and frequently includes health needs that are broader than medical interventions.

Health systems, therefore, need to be able to respond to provide both preventive interventions and those which focus on the case management of disease, all of which require advances in health service delivery mechanisms and collaboration with other sectors (Samb et al., 2010). To date, approaches to health systems strengthening that emphasise the control or containment of communicable disease have dominated policy and programming, with limited consideration of more chronic or lifelong conditions. This has led to weak, fragile and fragmented systems in many LMIC contexts, which have also been designed and shaped by donor priorities. Consequently, the medical management or cure of disease and disability is frequently prioritised due to the dominant perspective of medical practitioners in global health policy. This leaves significant gaps in health systems to be able to deliver a solid continuum of care that allows for: prevention, detection, referral, management (including both pharmacological and psychosocial), surveillance and monitoring, and quality of care assessment, in response to the management of disease and associated debility and disability (Samb et al., 2010).

Furthermore, person centred approaches that prioritise the beliefs and values of patients are frequently ignored or ill-considered. To be able to respond to debility and disability effectively within health systems, there is therefore a need to re-orientate approaches to health systems, strengthening towards a focus on multi-stakeholder and multi-sectoral partnerships that put the needs of patients and persons affected by disability at the centre of services. The recent health systems research (HSR2018) conference hosted in Liverpool provided a platform to discuss moving beyond the dichotomies of physical and mental health and disease and disability with health systems researchers, and to emphasise the importance of these issues in the global health systems strengthening research agenda. Box Seven below presents a summary of the session and the key learnings from the discussions that drew on several of the case studies presented throughout this report.

Box Seven: Improving Health Systems Responses to Chronic Disease and Disability: Addressing Medical and Psychosocial Needs in Essential Service Delivery?

Summary of a session hosted at the Health Systems Research Global Symposium in Liverpool in October 2018.

The following text reflects on the purpose of the session, followed by some of the key discussion points and reflections.

Session Hosts and Presenters: Rachel Tolhurst, Janet Price, Laura Dean, Oluwatosin Adekeye, Surekha Garimella, Paluku Sabuni, Hafiz Hussein

Session Purpose and Overview: The session was designed to share experiences of approaches in research, health systems development and delivery, to understand and address the realities of people living with chronic disease and disabilities, and how they are shaped by intersecting inequalities. The session began with a series of short presentations followed by an interactive fish bowl discussion that asked the audience to share their reflections and suggestions for priority areas in the development of a rights-based framework for action that could support dialogue between people affected by chronic disease and/or disability, activists, researchers, policy makers and service providers, to develop responsive services for all.

Key Discussion Points:

- Many of the presentations described key mental health challenges amongst people affected by chronic disease, debility and disability. Discussion participants raised that this is one of many “hidden issues” within the disability movement, along with other issues such as sexual disability and chronic pain. Chronic pain was described as over medicalised and insufficiently linked to mental health, which is often stigmatised.
- One participant shared examples from their work in north India, where they had found that most disabilities were interlinked with psychosocial disabilities, emerging as some of the most prevalent but also the most difficult to access treatment and support for.
- Psychosocial/mental health challenges due to trauma during conflict were highlighted by several participants as a significant challenge, particularly as psychosocial support services are weak – particularly in areas of prolonged conflict or crisis.
- Participants discussed the importance of preventive approaches, and the need for nuance and balance with supporting PWD to avoid “othering” them or implying that their lives are less valuable.

Key Take Home Messages/Reflections:

- The central importance of respect, dignity and autonomy for PWD and the role of health sector in promoting and building this.
- The importance of inclusion and participation of PWD organisations in designing services and decision making.
- Early access to preventive, curative, medical management and psychosocial services is critical.
- Attention to the practical and psychosocial support needs of carers is required, including family, community and frontline health workers.
- The importance of linkages between different service providers – even within physical or mental health services, moving from acute/crisis to chronic phases of illness is often ill-defined with insufficient service linkages.
- Peer support approaches through self-organised groups may be a helpful approach to enable shared problem solving, practical and psychosocial support.

The subsequent sections reflect on several key areas that are likely to be critical in re-orientating health systems to be more responsive to the needs of people with debility and disability in LMIC settings. They consider some of the key components that will be essential in supporting health systems in LMICs to move toward integrated care (United Nations, n.d.). Shifting disease burdens and a focus on chronicity of illness and associated debility and disability present a unique opportunity for health systems to provide a response to a “continuum of ill-health” at the primary health care level (Allotey, Reidpath, Yasin, Chan, & de-Graft Aikins, 2010).

1. Nothing about us without us: Prioritising person-centred health systems

Persons affected by chronic disease and associated debility and disability should not be passive bystanders or targets in the re-orientation of health systems. Rather, their beliefs and values should be prioritised in health systems strengthening. Throughout this document, individual case studies have emphasised the unique, multi-faceted experiences of disease and disability that are shaped by broader social and environmental factors. It is these interactions of health conditions with the physical, social and attitudinal environment that requires a holistic response to associated debility and disability. The “nothing about us without us” movement, led globally by the disability community, provides a strong network of disabled persons’ organisations (DPOs) that can be leveraged across numerous LMIC contexts to support in the design, delivery and monitoring of person centred health systems. The structure of these responses is likely to be unique to context and individual circumstance (Madden & Bundy, 2018).

Madden and Bundy (2018) site the International Classification of Functioning as a useful tool in the development of person centred health systems that prioritise inclusivity of persons affected by debility and disability, as it can provide a space for increased dialogue between health professionals and service users to:

- Promote improved communication between patients and health professionals.
- Enable patients to proactively and collaboratively set up their rehabilitation goals, building a stronger alliance with health care providers.
- Enable rehabilitation professionals to identify individual functioning limitations or environmental barriers, and develop a treatment plan that is patient centred.

2. Respond to issues of access in mainstreaming disability within health systems

People with a disability may or may not experience acute or chronic illness, and chronic illness may lead to varying impairments over time. Thus, like all individuals, people with disabilities have their own specific health needs which are diverse depending on subjective experience. There is evidence that suggests, however, that individuals with disability, particularly those based in LMICs, face greater challenges in accessing health and healthcare services and as a result have poorer health outcomes (WHO & World Bank, 2011). Exclusion in relation to healthcare spans several key areas, including: challenges in accessing health facilities due to both physical and economic barriers; poor quality of care associated with disability when reaching a facility based on attitudinal barriers of health staff; lack of inclusion or adequate adaptation of public health campaigns; and a lack of access to nutrition, water and sanitation services, which can exacerbate impairment (WHO & World Bank, 2011).

Whilst accessibility barriers are of paramount importance in mainstreaming responses to debility and disability within health systems, it is also critical that other access barriers are also considered. The Availability, Accessibility, Acceptability and Quality (AAAQ) framework provides a useful tool to allow for assessment of broader access barriers for people with disability when interacting with health systems (United Nations, n.d.). For example, in the earlier section on conflict, we were able to explore how specific services may or may not be available in times of crises. Anjali’s story in Box Three presented a snap-shot of community perceptions around disability and sexual and reproductive health and rights. Negative experiences of disabled women in relation to their SRH needs and

rights extends to the health service when they seek care. This is a clear example of where quality of services can be shaped by attitudinal barriers, such as when women with disabilities are denied maternal health services or abused by health staff when receiving treatment (Dean et al., 2017). The increasing focus on access to health services for people with disability is a huge step forward in prioritising their needs within health systems. However, as well as research and documentation of these issues, further work is needed on effective approaches for action to reduce existing service barriers.

3. Ensuring the provision of specialised services

Equally as important as mainstreaming debility and disability within routine service delivery is the need to consider strengthening service delivery platforms for specialised services for chronic disease and disability, such as rehabilitation and habilitation⁵ services. The benefit of the provision of these services within health systems delivery is that they should focus on the broader support needs of persons with debility or disability, prioritising broader health and wellbeing and ultimately moving away from the treatment of disease as a sole focus (Madden & Bundy, 2018). This focus may include educational, vocational or psychosocial support plans (United Nations, n.d.). Rehabilitation in many cases may involve the provision of technology or assistive devices to support individuals to obtain optimal functioning when interacting with their environment. As described when considering person centred health systems, the ICF can be used as a useful roadmap when collaboratively setting rehabilitation or habilitation goals between health workers and patients.

4. Community based rehabilitation

Enhancing sustainability of interventions and maximising inclusivity for people with debility and disability is essential. Community based rehabilitation (CBR) approaches provide a platform that can meet the basic needs of persons affected by debility and disability and their families at the community level. Provision of services at this level helps to keep people in their communities, thus enhancing opportunities for participation and inclusion. CBR has undergone a process of evolution, from a model which focused on medical care to that which prioritises multi-sectoral action to encourage access to, and maximise benefit from, education, empowerment, and health and social support systems for persons with disability. The new model focuses on the need for holistic support to persons with disability and their families, to ensure sustained improvements to quality of life. CBR also allows for context specific adaptations at the community level, which are likely to be essential in sustaining a continuum of care for chronic disease and associated debility and disability. CBR approaches have the potential to inform the implementation of the Care for Chronic conditions framework that explores key ways to re-orientate health systems toward the management of chronic illness, prioritising support for families and patients at the micro level as one of its key objectives (Allotey et al., 2010). Information sharing would support convening “chronic disease communities” and “disability communities” to learn from each other and enhance collaborative action. Three of the key learnings that have made CBR approaches successful are: prioritising participation at community level; developing strong partnerships across and within sectors; and eliciting government support to facilitate and fund the CBR process.

⁵ Rehabilitation is concerned with re-gaining skills or abilities that may have been lost due to disability or debility. Habilitation refers to gaining new skills, abilities or knowledge (United Nations, n.d.).

5. Improving the collection and use of disability related data against modified legal and policy frameworks

One of the key steps in disability mainstreaming is a review of legal and policy frameworks, particularly those linked to communicable and non-communicable disease, to assess their inclusivity. This will support in identifying areas that are essential for reform in upholding the rights of persons with debility and disability. Coupled with legal and policy reform (which can be lengthy and timely processes) is the need for the development of inclusive implementation frameworks. Such frameworks can also be developed in advance of policy and legal reform, and this may be a way to speed up the mainstreaming process. Once developed, it is critical that implementation frameworks also have a clear method for monitoring and evaluation, to be able to reflect on progress and most importantly how they are contributing to overall goals of enhanced support and participation (Allotey et al., 2010).

A key challenge in the monitoring and evaluation of revised implementation frameworks, and more broadly in advocating for the needs and rights of persons with debility and disability, is data. Article 31 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD) prioritises the collection and use of disability data in measuring progress against achievement of other articles within the convention (UNCRPD, 2006). Disability and rehabilitation data is, however, incomplete or lacking within most health information systems (HIS) in LMICs, regardless of whether they have ratified the UNCRPD or not (McPherson et al., 2016). For example, service delivery data is rarely disaggregated by disability and where it may be disaggregated it is not linked to other social stratifiers making intersectional analysis (described earlier) challenging. Disaggregated data not only matters for monitoring service use but is also essential in planning for service delivery (Madden & Bundy 2018).

There is a clear need to strengthen HIS in LMICs (and many HICs) to be able to collect and disaggregate disability specific data. However, to enable to strengthen systems there is first a need to develop a clear understanding of key definitions and concepts that will inform what and how data should be collected. Currently, data definitions are frequently subjective (causing wide variations in interpretations of disability prevalence) (McPherson et al., 2016), and data on impairments and/or health conditions is frequently used as a proxy for disability, which may underestimate need (McPherson et al., 2016). The ICF as a standardised framework is a useful tool in developing data definitions. The development of the Washington group short set of questions on activity limitation as a proxy for disability present an excellent resource in grappling with data definitions. These questions could become a useful gold standard in all HIS's to allow for the levels of data disaggregation required. Their implementation would need to be accompanied by capacity strengthening activities linked to data platform development and the training of health staff and/or enumerators.

Box Eight: Building Partnerships Between Eye Health and Mental Health in Managing Glaucoma in Northern Nigeria (Based on the PhD study of Dr Oluwatosin Adekeye)

The current prevalence of visual impairment in Nigeria is estimated at 1 million blind adults and 3 million visually impaired people, out of which 150,000 adults suffer from glaucoma. Strikingly, visual impairment is three times more prevalent in the dry northern Sahel region than in the southern delta region, and this has been associated with the dry, dusty environment and prevalent weather conditions. Loss of vision at presentation due to glaucoma, especially in one eye, has been found in 53% of patients, while loss of peripheral vision was found in 27%. Such high levels of visual impairment at presentation is mostly because patients are unaware of the problem and present late, only once vision loss has occurred.

Emotional reactions to a diagnosis of glaucoma can produce psychological distress (anxiety and depression). The gradual deterioration of sight initially prevents patients from recognising faces or finding their way in unfamiliar territories. Eventually, the patient requires constant care, while failure to contribute towards their upkeep in the family often leads to social exclusion, being unable to move about freely, inability to access social services and health care, increased poverty and ill health. Common patient reactions due to perceived negative consequences include: denial at the time of the initial diagnosis; anger at the loss of vision and having to give up favourite activities; anger at family and friends due to the need for greater dependence on others; anger at their doctors for not being able to restore sight; and fear of losing control over their lives and loss of self-respect.

The primary treatment for glaucoma is medical, which includes the reduction of pressure in the eye. Some treatments may also aim to improve the blood supply to the optic nerve. This is usually carried out by eye health professionals. However, based on the assessment of patients and the overwhelming psychological issues associated with the condition, building a partnership to ameliorate the mental health burden associated with glaucoma was essential due to the high prevalence rates of anxiety (58.9%) and depression (57.4%) in this group of patients. Through collaboration with patients, we established a number of patient-led support groups that brought together the eye health and psychiatric services in Kaduna State, Nigeria. When evaluated, participants exposed to a combination of mental health and eye health treatments had better outcomes in terms of coping and reduced emotionality.

Building the initial partnership between mental health and eye health was met with scepticism, as some health professionals did not see the need as their patients were not “mentally disturbed.” This is despite the ophthalmic nurses taking courses in psychology and sociology during their post-basic training. With engagement and presentation of the assessment data, all cadres of professionals began to be more enthusiastic in their approach and support of the support group that had been established.

6. Partnerships are paramount

Partnerships are central to the achievement of all the potential actions or approaches highlighted in this section. The discussion on access and CBR (point 4 above) emphasised the importance of multi-sectoral partnerships that extend beyond the health sector to include water, sanitation and hygiene (WASH). The description of the “nothing about us without us” movement and person-centred health systems also presented the critical importance of patients and communities in the design, delivery and monitoring of health systems. Box Eight and Box Nine both provide examples of how partnerships within the health sector are also critical in providing support for persons affected by debility and disability. Box Eight emphasises the importance of partnering across areas within the health systems to support patient needs and how the engagement of patients themselves can often facilitate and sustain this process. Box Nine highlights the role that the private sector (in this case a faith-based NGO) can play in improving social participation and quality of life of persons with debility and disability as a result of communicable disease.

Box Nine: Supporting Clarette to Gain Work Experience Through a Private NGO

Clarette, is 30 years old and a mother of a 3-year old girl. Clarette has been diagnosed with leprosy. After a thorn punctured her foot, she had a wound that could not heal, despite medication she received in health centres and local hospitals. Her family consulted witches, and nothing improved. She has visible infirmities on her feet and hands. She had been rejected by her family. Her family thinks that she has been cursed and that she should be chased out because her misfortune can reach other family members. The father of her child had fled when he had learned that she had leprosy. She has difficulty accepting that she is suffering from leprosy.

With the support of The Leprosy Mission (TLM), Clarette completed her graduate studies in business and accounting and she has been looking for work for some time but without success. The training was not appropriate to her. Clarette is now spending a few hours a week completing volunteer work at the TLM Congo office to get acquainted with the profession.

7. Financing and Social Protection

In addressing the links between poverty and disability and improving access to health services, health financing and social protection mechanisms are of critical importance. Mainstreaming disability within social protection schemes can increase access to resources, as well as reducing barriers to social and economic mobility, which in turn can promote health access and reduce exacerbation of impairment or the development of secondary impairments (Devandas Aguilar, 2017). To mainstream disability within financing and social protection, a few key adaptations may be required to respond to disability specific vulnerabilities. This can include, but is not limited to: adaptation of target mechanisms to level and frequency of need; ensuring the most appropriate mix of interventions based on need; policy reform; and adaptation to disability specific barriers, e.g. visibility (UNICEF, 2015). In relation to health financing, improving health information systems to collect disability disaggregated data as well as better information about communicable and non-communicable disease as described in point 5 above are essential as a first step in improving resource allocation in these areas.

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