

# Designing Policy Centric Disability Research in Resource Constrained Settings in the Global South: A Review of Key Concepts

Dilshan Fernando



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Contact: 12 Balcombe Place, Colombo 00800, Sri Lanka. +94 11 267 1160. [info@lirneasia.net](mailto:info@lirneasia.net)  
[www.lirneasia.net](http://www.lirneasia.net)

# **Designing Policy Centric Disability Research in Resource Constrained Settings in the Global South: A Review of Key Concepts**

## **1. Empirical problem of disability**

LIRNEasia's disability focused research has produced wide-ranging policy-oriented outputs. In this literature review, our aim is to contextualize these in the wider arena of disability studies in the Global South. In doing so, we intend to connect the policy research with the theoretical and policy debates about disability emerging from the Global South. Those debates include how disabling barriers are created by wrongful social policies, the congruence of policies and technologies in creating identities of people with disabilities (PWD), and the influence of technologies, mostly information and communication technology (ICT) based ones, on life-worlds of PWD. These are addressed in the subsequent sections of this review.

For LIRNEasia, in the beginning of its disability program, disability appeared as a major social problem, a barrier, that restricts people with disabilities (PWD) from fully participating in society. In this premise, two questions emerged: What can be considered as a disability? How to operationalize participation in society? The first question concerns the functional limitation of a disabled person – hearing, seeing, remembering, etc., while the second concerns the domains of life that are hindered by the disability – education, health, work, etc. The goal of this research was to understand how a robust technology driven policy, specifically information and communication technology (ICT) policy, could alleviate or minimize disabling barriers, allowing PWDs' full participation in society. In summary, the guiding hypothesis was that ICT related technologies (Internet, mobile phones, computers, and various digital assistive technologies), and

policies (laws, infrastructure, private sector solutions) could positively influence disabling barriers to generate positive outcomes in independent life of the PWD.

In section two, various definitions of disability are discussed. The social model of disability is introduced in that section with reference to the UN treaty on disability. In section three, the problem of categorizing disability is addressed by referring to functional, environmental, and identity-based conceptualizations. In section four, the focus of operationalizing participation in society of PWD is discussed, with reference to education and employment. In section five, the nature of ICT based interventions for disability is discussed. In section six, the difficulty of determining outcomes of disability policy and research is discussed with reference to measures, independent living and wellbeing. We conclude by outlining several pointers for future disability research focused on the Global South.

## **2. What is disability?**

Although disability appears as a straight forward empirical problem that need concrete inclusive practices, sociologists have pointed out that the prevalence rates depend on how one defines disability. For example, there has been an enormous increase in autism spectrum disorders since the 1990's – “autism epidemic” – and Maynard and Turowetz (2019) argue that the rules used for diagnosis has influenced the increase significantly. They argue that the narratives and cultures of what is viewed as autism has changed since the 1990's. Similarly, the prevalence of disability, although we openly admit that about 10% of the world's population is disabled according to the UN, and the interpretation of this figure, depend on what we understand by the term “disability.” Since the UN Convention on the Rights of Persons with Disabilities (CRPD) itself defines disability deemphasizing the health dimensions of it, many countries depending on their policy outlooks embraces different definitions.

### ***2.1. Defining disability***

Defining disability is a difficult due its coincidence of medical and social connotations. This is a point which has been recurring in many of the disability studies literature. As Mitra et al (2011) assert pertinently, “disability is complex, dynamic, multidimensional and contested” (Mitra, Posarac, & Vick, 2011; p.3). However, it is crucial to emphasize the paradigmatic shift in the way in which the debate over disability as a concept as well as a human condition has shifted in the last few decades (Mitra, Posarac, & Vick, 2011). As Harpur (2012) notes, identifying the “social constructed-ness” of disability in the CRPD itself, in contrast to the designation of it as just another medical condition that requires proper medical care foregrounds the direction in which policy efforts to tackle it should take place. Therefore, the “social turn” in defining disability provides the context to any research of it as a social problem.

Goodley's account (2011) of what is called the "social model" in critical disability studies literature is appropriate to make the previously discussed distinction clear. According to Goodley, disability is defined as a social condition; more precisely an 'effect' of negative social circumstances (infrastructures, attitudes, policies, etc.) that consequently constructs the condition of "disabled-ness". The clear distinction to be made with regard to this is the medical notion of "impairment" (visual, hearing, physical, intellectual, developmental, etc.). For this version of medically centered disability, impairment constitutes the whole of disability. Therefore, such a concept merely warranted suitable medical aid to "treat" the PWD, while ignoring the dimensions of social accessibility, inclusion, enabling policies, etc. On account of this, disability scholars have strived to articulate the social embeddedness of disability itself. In view of this "social model", impairment is separated from the disability, although the latter cannot prevail without the former.

## ***2.2. Critical disability studies (CDS)***

CDS scholars ventured to explore from the social model lens an entire array of problems and barriers associated with disability which were not researched before. As Oliver (1990) points out, this new scholarship informed a large number of social workers who worked with PWD, especially in the UK. Other commentators such as Levitt (2013) have pointed out that the impact of the social model will significantly improve if researchers take in to account the wide differences that exist in different country settings. For example, Levitt shows the importance of giving due consideration to determinants such as poverty level in country when applying the social model analysis, so that the results of such research can render the comprehension of disability in its broader context.

There have several other critiques on the social model itself, mostly conducted on premonition to expand the impact of the model. For example, Taub et al (2009) highlight the need of the time to recognize the interaction between the impairment (bodily states) and disability (external forces) in defining disability. Taub et al (2009) highlight the importance of the gender dynamics of disability. They claim that “disabled women’s experiences of impairment (e.g., pain, illness, and fatigue) must be acknowledged and included when addressing the disabling effects of social and environmental barriers” (Taub, McLorg, & Bartnick, 2009; p. 206). In this sense the social model has to accommodate the role that gender plays in disability. On the other hand, several researchers have pointed out an often overlooked “western-centric” dimension in the social model. For example, Grech (2009) claims that the social model is grounded on the concerns of western, white, urban, educated disabled academics in industrialized settings. He also aptly criticizes the social model for possessing the risk to be contextually and culturally inappropriate due its “universalist discourse” on disability. Furthermore, Hughes (2009) has highlighted the “somataphobic” aspects that emerge in the CDS scholarship when using the social model in a very narrow way.

Overall, two theses regarding the social model in understanding disability must be put forth. Firstly, the social model accomplished a break with the previous medical-centric identification of disability which championed the disability activist movements around the world (Goodley, 2011). Secondly, the model itself is not without criticism and shortcomings which are pertinently pointed out by many researchers as discussed before (Levitt, 2017; Taub, McLorg, & Bartnick, 2009; Grech, 2009; Hughes, 2009). Therefore, it must be emphasized that the social model approach is the inevitable comprehensive definition available to understand disability

currently, and should not be merely ignored due to its criticisms. But rather, the model should be appropriated adequately to give meaning to disability in the local contexts concerned.

### ***2.3. The UN CRPD***

Defining disability by way of a social model is further strengthened and justified by its enshrinement in the UN CRPD. As Harpur (2012) shows, the previous medical model tried to “fix” the people without sufficiently admitting that the PWD can live fulfilling lives if the social circumstances provide for it. Celik (2017) very eloquently states that the introduction of the CRPD in many ways shifted the paradigms of the disability debate by bringing a new dimension to the perception of “human” in the legal arena. She further states that the liberal notions attached to this perception of “human” such as “dignity” and “traditional autonomy” were forced to be redefined comprising the implicit dimensions of “vulnerability” and “relational autonomy” at the very heart of what is known as “human” (Celik, 2017).

### ***2.4. Global disability statistics from the social model perspective***

Fifteen percent of the world’s population (nearly 1 billion people and 1 out of 7 of the world population) lives with at least one form of disability. Coupled with this data, the social model persuades to conceive of disability as innate to all human beings, such that every person will one day experience some sort of disability due to aging, ailment or other reasons. In this sense every person on earth possesses just “temporarily abled bodies” (Goodley, 2011). Moreover, Harpur (2012) states that 20% of people living in developed countries also experience some form of disability. Based on these statistics, it is reported that with four or five times more likelihood, PWD are denied right to work (Harpur, 2012). This figure is claimed to reach 80% (the denial of right to work) in developing States.

The apparent dichotomy of disability between the developed and the developing world is clear. The problem is amplified in its effects due to incapability of the developing nations to cope with it by inventing innovative and structural policies. With a closer resonance to this deadlock, Zhuang (2016) finds that disability policy should be seen as an effect of the “welfare state” in the case of Singapore. As he further states “in Singapore, disability policies can be said to de-commodify disabled people vis-à-vis the labour market. Policies such as transport concessions and subsidies to utilize educational and day care services reduce disabled people’s need to earn a wage” (Zhuang, 2016; p. 628).

Therefore, it is the very impossibility of welfare state policies in poorer low- and middle-income countries (LMIC) that generate the varying levels of disabling experiences for the PWD living in those countries. Further, it becomes much productive to read the global disability statistics, especially concerning the dichotomy of developed and developing countries, by foregrounding the social model as a better interpretation.

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### **3. Types of disability**

#### **3.1. Functionality**

There is a troubled history of categorization of people. For many PWD, categorization according to different types is experienced as a violence, something that created their existing barriers and sufferings. Categorization was used as a means to castigate and discriminate people (Lamont, 2012). Once one is deemed deaf, for example, then certain civil, political, and economic rights are revoked, and one is made dependent upon either social services or a guardian. In India (Department of Disability Affairs), the current categories of disability stand as follows:

- I. Physical Disability
  - a. Locomotor Disability
    - i. Leprosy Cured Person
    - ii. Cerebral Palsy
    - iii. Dwarfism
    - iv. Muscular Dystrophy
    - v. Acid Attack Victims
  - b. Visual Impairment
    - i. Blindness
    - ii. Low Vision
  - c. Hearing Impairment
    - i. Deaf
    - ii. Hard of Hearing
  - d. Speech and Language Disability
- II. Intellectual Disability
  - a. Specific Learning Disabilities
  - b. Autism Spectrum Disorder
- III. Mental Behavior (Mental Illness)
- IV. Disability caused due to-
  - a. Chronic Neurological Conditions such as-
    - i. Multiple Sclerosis
    - ii. Parkinson's Disease
  - b. Blood Disorder-
    - i. Hemophilia
    - ii. Thalassemia
    - iii. Sickle Cell Disease
- V. Multiple Disabilities

However, categorization is perennial to alleviate barriers. A useful functional matrix of categorization is the Canadian Longitudinal Study on Aging (CLSA). It categorizes disability of aged individuals according to the commonly referred strata of “basic activities of daily life (BADL)” and “instrumental activities of daily life (IADL).” According to this classification, BADL refer to the fundamental tasks an independent adult needs to accomplish at a private dwelling, namely; bathing and showering, personal hygiene and grooming (including brushing/combing/styling hair), dressing, toilet hygiene (getting to the toilet, cleaning oneself, and getting back up), functional mobility, often referred to as "transferring", as measured by the ability to walk, get in and out of bed, and get into and out of a chair; the broader definition (moving from one place to another while performing activities) is useful for people with different physical abilities who are still able to get around independently, self-feeding (not including cooking or chewing and swallowing) (Raina, Wolfson, Kirkland, & Griffith, 2018). On the other hand, IADL refer to more advanced functions which include but not limited to, public mobility, preparing meals, managing money, shopping for groceries and other necessities, taking prescribed medications, using a telephone or a mobile phone, religious observances. Moreover, the American Occupational Therapy Association (Roley, DeLany, & Barrows , 2008) lists 12 activities which can be termed as “instrumental” in one’s daily life:

- I. Care of others (including selecting and supervising caregivers)
- II. Care of pets
- III. Child rearing
- IV. Communication management
- V. Community mobility
- VI. Financial management
- VII. Health management and maintenance
- VIII. Home establishment and maintenance
- IX. Meal preparation and clean-up
- X. Religious observances
- XI. Safety procedures and emergency responses

## XII. Shopping

There are other broader classifications that are also used in disability research. The WHO International Classification of Functioning, Disability and Health (ICF) is currently the internationally accepted AT classification used world-wide. The Washington Group on Disability Statistics (WG) has simplified the rather rigorous and complicated WHO classification by categorizing the daily activities of an independent adult into three main criteria: 1) Basic Activity Domains; 2) Body Function Domains; and 3) Complex Activity/Participation Domains. These three macro-categories are then further segmented in the table below.

*Table 1: Washington Group Matrix*

<b>Domain</b>	<b>Subdomain</b>
Basic Activity	Communication
	Mobility
	Hearing
	Visual
	Cognition/Remembering
	Upper Body
	Learning/Understanding
Body Functions	Affect
	Pain
	Fatigue
Complex Activity & Participation	Activities of Daily Living (BADL)
	Instrumental Activities of Daily Living (IADL)

	Getting Along with People (GAP)
	Major Life Activities (MLA)
	Participation in Society (PS)

*Source:* (Scientific Foresight Unit (STOA), 2018, p.12-13)

### **3.2. Environment**

There are plausible arguments that view definitions of disability based on functionality as reproducing medical notions on barriers. Functionality is analogously identified with bodily deficits. The alternative proposition of such arguments is the environment. Those who view disability as something emanating from society, and not the individual, find the environment as the site of disabling barriers (Pryor et al., 2018). Based on this definition, types of disability emerge from different types of environmental in-accessibilities: built environment, digital environment, urban design, rural spaces, transport services, etc.

One of the main motivating factors for this study, is the growing push to make mobile phones, computers, and the Internet accessible to everyone, which includes the PWD. Accessibility of the environment is essential for disability inclusion (Cook & Polgar, 2015). The universal design of the analog and the digital space, as opposed to mere accommodations, caters to this well. In the last decade, there has been a rapid increase in the universal design of ICTs aimed at improving their accessibility to PWD (Persson et al., 2015). ICT, a mobile phone or a computing device often connected to Internet, is a cheaper form of technology and indicates significant use across people in different income levels (Lazar & Stein, 2017). Evidence from Myanmar and India show that the use of ICT in a developing context, for basic and instrumental activities of daily life of the PWD (Raina et al. 2018, p. 81) is extensive and often experienced as an assistive function (Hurulle et al. 2018; Vihara Innovation Network 2019).

### 3.3. Identity

The last way to categorize disability is by identity groups which are self-referential. Negotiating identity and difference is a challenge to any disability related process. In the rich ethnography, *Valuing Deaf Worlds in Urban India (2015)*, Friedner discovered how Bangalore's deaf people remained closely within the boundaries of the deaf community in pursuing their daily lives. Not just their activities, but also their values, beliefs, and aspirations were intertwined with what they referred to as "deaf deaf" relations, i.e., those with other known deaf people (Friedner, 2015). Moreover, these deaf people viewed their quality of life associated with "deaf development," the idea that trusts inculcation of language, social, cultural and job skills is related only to deaf-centered institutions and structures (Friedner 2015, p. 2). In other words, Friedner's ethnography presents a thoroughly deaf-centered life world that thrives through its *difference* from others.

Sameness coexists with difference, and is a crucial part of it in the case of "deaf development" (Friedner 2015, p. 2). Note that it is the *within* deaf sameness that is invoked here. While it is true that Bangalore's deaf community internalized a value system that only pertains to itself, their cohesion as a community nonetheless was produced through what the "sameness work" (Friedner 2015, p. 5). From the stand point of a deaf person, sameness work is about "copying" the rituals and practices of other deaf people who belong to that group (p. 5). While it seems that copying and sameness work are not necessarily gestures of liberation that seek to undo disabling barriers, from deaf people's standpoint, these micro-level processes represent innovative spaces that they have co-created to thrive as a community.

Deaf sameness work and deaf development mark the complexity of disability as an identity by diluting it. Note how the identity creation discussed above through difference and sameness pertains only to the deaf community in Bangalore. This means that other types of disabilities are also different from deafness. Still more, even deaf identities outside Bangalore are different. Therefore, to theorize intersectionality in a meaningful and methodologically useful manner, negotiating difference as an ontological feature of identity is important (Benhabib, 2002; Friedner, 2015). Such a view will contextualize and historicize intersectionality in a way that will not fetishize homogeneity.

The identity-making dimension of disability policies must engage with these complex dynamics to make policies workable. For instance, “deaf deaf sameness” (Friedner 2015, p. 2), the tendency that deaf people in urban Bangalore city (and also in other parts of India) look for deaf role models as relatable social networks to build their life-worlds and achieve “deaf development” (p. 2) indicates that the social inclusion that they seek is not individually determined. Moreover, their deafness also seems to be contained within a deaf world, one that is occupied by many. This is why deaf people “help support” (Friedner 2015, p. 156) each other for deaf development’s sake. Nonetheless, they pursue a collective liberation.

This kind of collectivity is different from the rhetoric of “independent living” and “self-help” surrounding the SMD (Oliver 1990, p. 120). Notably, the deaf community in India are keen on “*help support*” than “*self-support*.” The ideas of independent living are also contrastingly different in the account of Friedner (2015). While the deaf experiences in India cannot be generalized to all of Global South, they are nonetheless indicative of the foundation of disability inclusion in that part of the world: i.e., in the collective.

This foundation allows for collective wellbeing to be a primary objective of disability policy in the Global South. Mitra (2018a, 2018b) describes that the human development model of disability is founded upon the capabilities approach advocated by Sen (Drèze & Sen, 1989). According to this approach, public action of the welfare state should not be just concerned with the provision of primary/public goods. Rather, it should also be concerned with directing/re-directing the resources for people to lead a socially useful and meaningful life. For this approach, income and wealth alone are not adequate measures of human development and wellbeing. In this sense, Global South theories of disability must concern with enhancing the capabilities of the various disabled communities.

Intersectionality is a powerful analytical tool that helps to understand the complexity of social life and identity. It is often misunderstood as the adding up of separate identities – like race and gender – to form one complete identity. However, its novelty is theorizing the hidden corners of oppression that are complicated and multidimensional. Accordingly, theories of disability policy cannot understand disability separately from other social locations like gender, class, caste, ethnicity, citizenship, and religion. In practice, since intersectionality is defined “as an analytic interaction”: i.e., “a nonadditive process, a transformative interactivity of effects”(Choo and Ferree 2010, p. 131), policies directed at eliminating disabling barriers must recognize that some of these barriers are interlinked with other non-disability related barriers. For example, Upadhyay (in Addlakha 2013) describes how fatigue is a ubiquitous experience among PWD across several types in India (p. 181). What is interesting is that this fatigue – in climbing stairs in poorly accessible buildings, using inaccessible public transport, or simply trying to indicate by sign language that a deaf person cannot communicate in speaking to those



who don't understand it – is intrinsically connected to the age of the person, the gender, or even the type of impairment. Now, to address such an issue with an accurate policy response, one needs to recognize the intersectional experiences of the disabling barriers. In the eyes of policy, a homogenous category of disability should not exist. It must recognize the internal heterogeneity of identity (Crenshaw, 1991; Hill Collins & Bilge, 2016; R. Rose *et al.*, 2021), and focus on capturing the unique experiences of old PWD, women with disabilities, immigrants with disabilities, Muslims with disabilities, or children with disabilities.

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## **4. Operationalizing participation in society**

Full participation in society can be operationalized in multiple ways. The CRPD itself lists many domains that inclusion should extend to. To demonstrate the choices to be made using a social model approach, education and employment are discussed as two domains of life where PWDs' full participation is aimed. The same approach can extend to other domains like health inclusion, financial inclusion, and social networks.

### ***4.1. Inclusive Education***

The widely accepted principle of organizing the education bureaucracy to support children with disabilities (CWD) is through inclusive education rather than segregated education (Elton-Chalcraft et al., 2016). Inclusive education means “child's presence, participation, acceptance, and achievement in mainstreamed schools whenever possible” (Muttiah et al., 2016, paragraph. 2). Whereas segregated education policies aim to remove the CWD from mainstream schools and educate them in separate settings, however much they intent to be inclusive (Ahsan & Burnip, 2007; Das et al., 2013). Therefore, social model-based policy frameworks should devise assistive technologies in mainstream classrooms to improve the learning experiences of CWD, while addressing the macro level broader issues of inclusion such as training teachers for inclusive educational practices, preparing inclusive syllabi , and streamlining bureaucracies and administrative practices (e.g., inclusive admission procedures) (Bhatnagar & Das, 2013; Furuta & Alwis, 2017; Hettiaarachi et al., 2018).

### ***4.2. Supported Employment***

For employment, the aim of many LMIC has been to implement “supported employment” programs where anyone who wants to get a paid job is facilitated to do so bet partnering the employers, job seeking person with disability, and the support worker. In India,

pilot programs of this nature have proven to be successful. In selected Indian states, match-and-support and support-and-match programs where support workers are continuously engaged to aid the PWD (in this case people with intellectual disabilities) in their workplaces have been successful (Chandrasekaran et al., 2021; Jagannathan et al., 2020). As seen, these are mostly labour-extensive programs. Research is seldom done on to find how digital technologies can reduce transactional costs and labour shortages, to provide better supported employment services.

Importantly, these programs help to avoid the stalemate created by existing laws in LMIC, where although laws exist, the labour force participation of PWD remain at very low levels. Out of the one billion PWD living in the world (approximately), at least 800 million are of the working age (ILO 2015). In Europe, 60% of the PWD participate in the labour force as opposed to 72% of the non-disabled people (Fundación ONCE et al. 2019). In India, an enormous 73.6% of the PWD don't participate in the labour force, where 68% of them live in rural, underdeveloped areas (Shenoy, 2011). Although data on the employment of PWD is hard to find (Fundación ONCE et al. 2019), the above data clearly show that there exists a global polarity of disabling barriers with regard to work opportunities.

To illustrate the stalemate in Myanmar, the government has taken a series of actions to support PWD in the past decade. Many of these actions are limited to legislation and policy drafts. Ratification of the CRPD in 2011 (Ministry of Immigration and Population, 2014) is a major victory that the entire disabled population achieved in their pursuit for freedom and dignity. This step paved way for many national legislations that helped to address the issue of inclusive development in domains such as accessible public transportation, digital access and

other accessibility problems faced by the PWD. However, amidst several national policy actions, Hurulle et al (2018) found that many PWD in Myanmar continue to face a vast number of discriminatory practices in their lives, which remain largely unexplored and unaddressed effectively (Hurulle, Fernando, & Galpaya, 2018). Particularly, although work support committees have been established, the overwhelming majority of PWD in Myanmar don't work. Meanwhile, it must be highlighted at this point that although the issues of disability in Myanmar seem graver, there barely exists any reliable literature on this topic apart from the studies already cited here.

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## **5. ICT based interventions**

### ***5.1. ICT-based assistive technologies in the Global South***

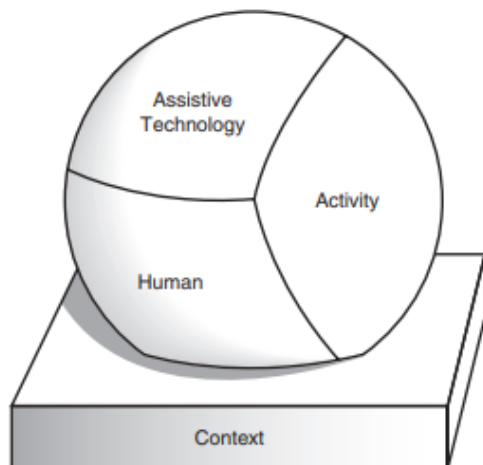
A substantial report aimed to introduce a framework to assess and contextualize the ICT based AT that aid PWD, and to provide a comprehensive list of what can be considered as AT products with ICT components was published by LIRNEasia in 2021<sup>1</sup>. Therefore, in this section, our aim is to summarize the state of AT-use in LMIC in Asia and to consider the effects on the wellbeing PWD.

AT shape not just action, but also identities (Ravneberg & Söderström, 2017). That is, while a hearing aid or a wheelchair helps the functional difficulties of a person Persson *et al.* (2015) suggest that the question of the accessible space “should move from ‘what am I’” as a person “to the question ‘what role does my different, constantly changing levels of ability play in this context’?” (p. 522). This suggestion is a complex characterization of identity in a disability context where “what I am” is intersected with my “constantly changing abilities” ((Persson *et al.* 2015, p. 522). Echoing this identity, in the “Human Activity Assistive Technology (HAAT) model,” the person engaged in an activity within chosen environments, using AT is mapped as an inter-relational AT ecology (Cook and Polgar 2015, see figure 1). This order offers the person (with a disability) the central focus in the use of AT. Hersh *et al.*’s definition of AT (as quoted in Cook & Polgar 2014, p.3) follows from this: “products, environmental modifications, services, and processes that enable access to and use of these products, specifically by persons with disabilities and older adults (2008a).” A similar definition of AT is: “any intervention involving assistive technology products and environmental adaptations to address a person’s individual

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<sup>1</sup> See [Assistive Technologies Aided by ICT \(Report\) — LIRNEasia](#)

problems related to disability in daily life, education, work, leisure and social life” (Salatino *et al.*, 2018, p. 238).



*Figure 1: HAAT model of AT*

*Source: Reproduced from Cook & Polgar 2015 (figure 1-1)*

It is relatively well-accepted now that ICTs, especially smart phone applications, have *assistive* functions – function as a regular AT – and can improve the quality of life of PWD (Doughty, 2011). Others have pointed out using i-pads as AT (Chmiliar & Anton, 2015). The underlying idea is that of AT mending the disabling barriers created by the inaccessible environment (see figure 2).



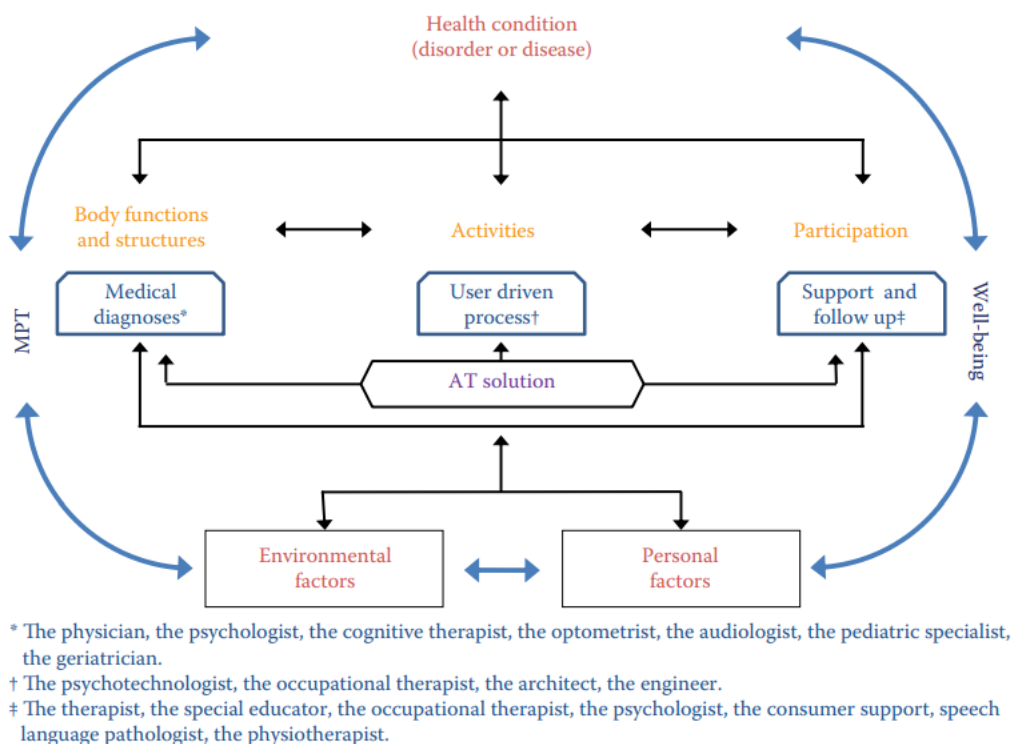


Figure 2: ATA process ideal model under the lens of the ICF biopsychosocial model (Reproduced from Federici & Scherer, 2018, p. 23).

For Karki *et al.* (2021), “lack of accessibility, eligibility, reachability and affordability” are the main barriers associated with access to AT for PWD in Nepal, India and Bangladesh (p. 1). To mitigate the gap, they propose “increased community level awareness, increased government funding and a community based, medically informed flexible social model of AT services” (p. 1). Borg *et al.* (2012) also find that affordability is the main barrier to acquisition and use of AT by PWD in LMIC. They also claim that factors like age, gender, type of impairment and socioeconomic status affect the use of AT. Access to affordable AT is even

closely connected with the achievement of Sustainable Development Goals (Tebbutt *et al.*, 2016).

In Bangladesh, based on a cross-sectional study, only 7.1% of the PWD reported of using any AT, and 71% self-reported an “unmet need” for AT (Pryor *et al.*, 2018, p. 1). AT use was also found to be positively associated with age and self-reported functional difficulty (Pryor *et al.*, 2018). Furthermore, the proportion of people using AT seems to be higher for mobility than for sensory and cognitive difficulties (Pryor *et al.*, 2018).

Although there is a grave need to improve availability, accessibility, acceptability, adaptability, affordability, and quality of AT products (Tangcharoensathien *et al.*, 2018) in the Global South, this is impeded by the lack of a single entry point system (SEP) that delivers the required services. An SEP is defined as:

A system that enables consumers to access long term and supportive services through one agency or organization. In their broadest forms, these organizations manage access to one or more funding sources and perform a range of activities that may include information and assistance, preliminary screening ... assessment of functional capacity and service needs, eligibility determination, care planning, service authorization, monitoring, and reassessment (quoted in Penton & Gustafson, 2014).

Therefore, decisive public action policies must design equitable SEP gradually to mend the gap of AT use.

## ***5.2. Limitations of ICT-based solutions***

In providing an overview of the general limitations of the ICT's in connection to Disability, it must be noted from the outset that many researchers have confined their findings to

the domain of what is called “digital exclusion” or in broader terms “digital divide”. Moreover, LIRNEasia’s research has comprehensively documented the accessibility and affordability issues concerning ICTs in the Global South. In this way many have neglected to analyze in a deeper sense what the ICT-based solutions cannot address among the disabling experiences.

Macdonald and Clayton (2013) defined “digital exclusion” as “a lack of access to and use of information and communications technology (ICT) resources” (Macdonald & Clayton, 2013; p. 705). They further claim that the idea that PWD are being socially included due to technological advances seems to be a misconception based on their empirical findings from the UK. Their research was focused on five domains of social exclusion (education, employment, social networking, independent living and healthcare) where they found no statistical evidence to suggest that digital technologies had improved in any of these domains for PWD (Macdonald & Clayton, 2013). However, they McDonald and Clayton (2013) insist that their research do not suggest that digital technologies cannot improve the lives of PWD, but rather that their access must be improved to all members of society rather than to a few who can afford them. Hence it is clear that what they find as a limitation of the ICT’s is in fact a matter of limited accessibility.

Furthermore, Watling (2011) show empirical evidence from the UK to testify the fact that many PWD do not own broadband internet services at their dwellings. Given the alarming nature of the percentages (32% of the persons with hearing impairments, 36% of the persons with physical impairments, 46% of the persons with vision impairments), Watling concludes that the ‘computerization of welfare’ should address the practical realities of the issues faced by PWD (Watling, 2011). In contrast to Watling’s findings, based on the findings of Hurulle *et al.* (2018) and as discussed previously, it becomes clear that although home-based broadband services may

be rare among the PWD, mobile phones with internet appears to be a growing a possession among an overwhelmingly large population of the PWD.

Simpson (2009) observes that ICT has the potential both to enhance access for the PWD and to contribute to creating more division and new forms of exclusion. Simpson thus highlights the importance of addressing the accessibility and usability of technology as it continues to develop and spread (Simpson, 2009). While the 2013 UNESCO report on “ICT for Disability-Inclusive Development” (UNESCO, 2013) also narrows their projections on possible limitations of ICT concerning different domains of Disability such as education, healthcare, etc. to only cost of AT’s, lack of accessibility and lack of better policies.

With all these accounts of the limitations of the ICTs, including that of UNESCO’s, what is noteworthy is their neglect of ICT limitation beyond the obvious accessibility issues. Many researchers have therefore confined their observations on the limitations of the dynamically changing but ever promising ICT-based solutions to disability to mere accessibility issues. What they clearly neglect is the whole terrain of disabling experiences that remain and unresolved and to a larger extend unresolvable using technology (what is called macro aspects in this research – which will be explored later). Our hypothesis here is that urbanization and employment as disabling experiences are two such terrains that remain outside of what is solvable through technology (and ICT) and are also constrained by the negative political economic determinants of underdevelopment which make the policies of developed nations inapplicable.

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## **6. Outcomes of enabling policies and technologies**

Measuring the outcomes of effective ICT policies on disability is a difficult task. It is particularly difficult to determine the outcome variable in disability policy that is still emerging and that lacks evidence in the Global South significantly. Given the lack of evidence, what can be outlined are general pointers to compare different variables. Various outcome measures have been considered in literature: wellbeing (Mitra, 2018b), welfare (Jayasuriya, 2001), happiness (Addlakha, 2013), economic growth (Mitra, 2018b), and social cohesion (Drèze & Sen, 1989).

### ***6.1. Independent living***

Although contested heavily as a notion that overlooks the interdependent nature of human life, it is still worthwhile to assert that independent living is not so much a negative notion as well. In Japan and South Korea, the notion of independent life expanded to a broadly supported movement known as the “independent living movement” which began in the 1960’s in USA (Hayashi & Okuhira, 2008). In the UK, the independent living fund (ILF), which closed in 2015, was a publicly supported and well regarded public action program that assisted PWD to lead an independent life (Porter & Shakespeare, 2016). According to Collin Barnes, independent living has four basic assumptions:

- 1) that all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth; 2) that anyone whatever the nature, complexity and/or severity of their impairment has the capacity to make choices and should be enabled to make those choices; 3) that people who are disabled by societal responses to any form of accredited impairment—physical, sensory or cognitive—have the right to exercise control over their lives; and 4) that people with perceived impairments and labelled ‘disabled’ have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers (quoted in Giermanowska et al., 2021, p. 406).

However, it is important to emphasize that independent living movement in the West was supported by a strong institutional network with public funding, and it would be difficult to imagine the thrust of the movement towards supported living without this background (Helgøy et al., 2003). The disability benefits infrastructure is also well-entrenched in the developed West (Michalos, 2014). Therefore, arguably, independent living research in the Global South, where public funding for such benefits is extremely limited, need to approach it differently. How it should be an open questions that needs empirical evidence. Whether technology could substitute in any sense the role played by disability benefits by providing novel opportunities, though appears plausible, need evidence as well.

## **6.2. Wellbeing**

In recent research, wellbeing is often used as a better outcome variable. Wellbeing is a multidimensional notion covering “material wellbeing, health status, personal activities, social relationships, and economic security” (Mitra et al. 2020). However, it still needs to be understood in the context in which it is assessed. To study wellbeing in a disability context, it needs to be conceptualized as an outcome of the non-inclusive way in which society is organized, combined with the person’s health (Costa-Black et al. 2013).

In *Frontiers of Justice (2007)*, Nussbaum describes how Sen’s capabilities approach is premised in contrast to the well-known theory of justice by Rawls. Underlying Rawls’s theory is the idea that income and wealth are the basis of human wellbeing. Arguing against this, Sen proposes a new framework of measuring wellbeing, where income and wealth are considered as mere proxies in achieving it. In contrast, capabilities focus on giving the necessary supports to lead a fulfilling life. As Nussbaum shows, this idea of capabilities assumes that there are varying



needs of resources for people. For example, a mobility impaired person might possess the same income and wealth like a non-disabled person. However, that person may be “unequal in capability” (Nussbaum 2007, p. 164) in comparison to the latter. In such a case, listing out the capabilities that different people need proves to be ideal than listing primary goods to achieve a certain income and wealth (Nussbaum, 2007).

Scholars agree that wellbeing as a multidimensional concept involving an individual’s and collective’s choices and values serve the purpose much better than other concepts (Mitra, 2018b). The main reason for this is that wellbeing advances and is embedded in the capabilities approach of human development (Mitra, 2018a). It is a “people-centered” model that goes beyond narrow understandings of social development based on economic growth (Mitra 2018, p. 13).

When collective capabilities of a group are invoked, measuring the impact of policies on their wellbeing has proved useful. For example, in South Africa, Graham *et al.* (2013) used the capabilities approach to understand the impact of policies affecting the education of PWD. The main implication of this study was that the impact of policies aimed at loosening the “poverty-disability nexus” (Graham et al. 2013, p. 324), especially in urban contexts, can be better understood by finding out how the wellbeing of PWD changed through them. Furthermore, because of its connection with the capabilities approach, and also because it is a changing concept, wellbeing strengthens and supports the processual nature of disability policies (Mitra, 2018a, 2018b).

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## **7. Conclusion**

In conclusion, few considerations for future research on disability in LMIC in the Global South can be listed. Firstly, not just social model approaches, advanced and holistic versions of it should frame the overall definitions of disability, moving away from medical/deficit notions. Secondly, research can benefit from using more fluid and hybrid categorizations of disability, rather than sticking to statistical kinds. As pointed out, functional, environmental, and identity-based categories can be decisively used for different contexts to obtain nuanced understandings. Thirdly, operationalization of participation in society must be focused and limited. A large body of literature exists for many domains of life, treating each of them as a specific form of disability, where education and employment are the mostly discussed ones. For optimal results for policy formation, research select domains instead of use them indistinctively with functionalities and environments. Fourthly, outcome measures of disability have significantly changed in the past decade and will continue to change for better outcomes for PWD. Therefore, research must benefit from these contemporary debates, while for now, wellbeing appears to be the most reasonable and widely used category. Finally, ICT based technologies have significant viability to alleviate some of the most pressing disabling barriers affecting poorer PWD in LMIC, that need to be part of the macro level policy frameworks.