How does access to Assistive Technology mediate recourse to Disability Justice for urban poor people?

A study centring the experiences of disabled slum dwellers in Freetown, Sierra Leone

A thesis submitted to University College London
in partial completion of the degree of Doctor of Philosophy

Victoria Austin

I, Victoria Patricia Austin, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

"AT is part of our fundamental rights. It makes us who we are. I am a disabled person. I have accepted that fact. I cannot deny that. But what makes me functional is my AT. So, I think it's a right, not a privilege."

Disabled Slum Dweller, Freetown, SL

“When the day comes we step out of the shade,
aflame and unafraid,
the new dawn blooms as we free it.
For there is always light,
if only we are brave enough to see it.
If only we are brave enough to be it”.

***‘The Hill We Climb’,* Amanda Gorman**

Impact Statement

To derive impact from this study I have published two papers (Austin, 21; Austin 22), the latter of which was in a journal special edition edited by the author of the Global Report on AT, seeking to set our new avenues for consideration on AT access. As Director of the Global Collaborating Center on AT access, at UCL, I have raised *AT for what* as a topic for the further contribution of GDI Hub and a thematic strand of work is being developed. It is intended that this will inform the future contribution of the Collaborating Center to delivery of the WHO GReAT report.

The question of a (disability) justice framing of AT interventions has been raised in the second phase of the AT2030 project, too, beginning in 2023, and I have gathered resource to further the development a Disability Justice (DJ) framework for AT over the coming 18 months.

The thinking in this thesis has also informed teaching on the MSc Design Disability and Innovation module Future Global Technologies for Disability and Development, led by UCL, over 3 years. It has also informed the content of guest lectures I have given across UCL and across our partnership, too. Plus I was privileged to be invited to Geneva to give a talk at the launch of the GReAT report, and this work informed that contribution. I also based my contribution to a Side Meeting at the Conference of States Parties to the CRPD at the UN in New York, in 2022, on much of this study.

Without the thinking that I have done for this PhD, I would not have been able to guide the AT2030 programme with the insight of the impact of AT access on the poorest people. We are currently bidding for additional research funding (UKAID, EPSRC) based on some of the findings of this work, and the other 150 studies done so far for AT2030.

I intend to return to SL to share the findings as soon as funding, health and travel allow.

Abstract

This thesis addresses the central question of the role of Assistive Technology (AT) in mediating recourse to disability justice, centring the experiences of disabled slum dwellers in Freetown, Sierra Leone. Taking evidence from six datasets collected across four years, the study maps the local experience to the national and global picture offering a strategic reflection on the current state of work in the sector.

The evidence from Sierra Leone (SL) reveals that quality AT is missing for almost all poor, disabled people. A novel finding from the research is that the lack of AT is most apparent for those who live in mainstream mixed urban settlements where disability identity is stigmatised and often hidden. Disabled people living together in an autonomously-organised settlement did – mostly - have AT, indicating further investigation into the role of collective action and autonomous organisation would be fruitful.

Picking up themes emerging from the SL evidence globally, the study reveals that the AT interventions of core actors do not align with a single common operational framework. Borrowing from Amartya Sen's seminal provocation *Equality of What*? (Sen, 1980), *AT for what?* becomes a pertinent question in the face of this dissensus. The study finds that the provision of AT within an operational framework of Disability Justice would better ensure the needs and aspirations of poor disabled people were prioritised in investment and priority setting. The thesis proposes, and tests, the potential configuration of a disability justice framework, as a basis future work can build from.

Taken as a whole, the evidence presented in this study suggests that the claims for disability justice (including access to AT) of urban poor disabled people are often subjugated to background conditions, sitting behind the life-and-death claims for the basic need of life for the whole community (water, shelter, food). Therefore, any framework for disability justice must itself be linked to a broader push for justice for all poor people to be meaningful and impactful. Similarly, any broad social justice movement should place disability justice at its heart if it intends to drive for progressive change that benefits all. Finally, this study finds that AT is more than a commonplace element of the struggle for justice due to its fundamental necessity as an enabler of participation. The evidence suggests that AT can be viewed as a *transitional demand* of Disability Justice.

Acknowledgements

To begin, I cannot find better words than those of the inimitable crip activist, writer, queer, disabled femme of colour Leah Lakshmi Piepzna-Samarashinha, who, in her book *Care Work: dreaming disability justice* (Piepzna-Samarasinha, 2018) writes:

> *"this [work] is emphatically not the product of a single smart person's brain. It was made through community conversations, organising efforts, arguments, fuck ups, terrible challenge, Crazy brilliant ideas and leaps of faith".* (p9)

The nature of a PhD study is as an individual pursuit. It seems, to me at least, perhaps the greatest learning it involves is that one has to surmount the challenges presented by one's own mind, time and time again. The capitalisation of 'Crazy' also feels wholly relevant to my experience of pursuing this work, while managing two mental health conditions: both creative and bewildering. Yet, it is also fundamentally true that the ideas contained within these pages have been formulated in community, through discussion and challenge, reading and raging, and quiet moments of breakthrough. Therefore, I must honour the community that helped me create this thesis:

- To the people in Sierra Leone who allowed me to be a part of their journey if only for a short while - I owe you a debt, and I shall continue to advocate for your right to advocate for yourselves, in every conversation I can. Always.
- To the staff and students at UCL, including my supervisory team, with whom I have grown up academically since re-joining in 2015 - thank you for giving me a home that was safe to learn in, from where I can give back. It is an honour to be part of building the future as part of UCL East.
- To our brilliant team at GDI past and present, who grew with me, who gave me time to think, challenge me daily, and who all get up every day to 'change the world a little bit'. You are awesome and it is always a privilege to work alongside you.
- To those in the global movements for disability justice and AT access (not the same thing as anyone who reads on will find out) – you have been so vital to my learning that I cannot do justice to my honour at being part of the things I have been able to over the past half decade.
- Thank you also to FCDO for supporting AT2030, giving us the motivation to try new things and the permission to get some wrong.

You all know who you are; I name none of you for fear of forgetting some of you. Thank you deeply.

Huge gratitude is also due on a personal level to friends and family that spurred me on, let me break down, built me back up again, and provided fun and fancy when I needed a distraction. I couldn't have done it without you.

Jackie you are the most brilliant and the bestest best friend I could have ever asked for. Thank you. Maria, thank you too - you know why.

To Barney in the moon, and Yogi in our arms, your waggy tails and furry smiles have brought joy to the dark hours so many times. A-woof!

These have been hard years for everyone. I am no exception. Daily, I dissuade our staff and students from taking on too much. Yet I believed it would be possible for me to undertake this PhD in four years, despite having a full-time (huge) job, two mental health conditions, and (for about two years in the middle) Long Covid. I can admit now that it wasn't the best idea. I (nearly?) broke several times. I learned so much about myself. But however hard, the knowledge I gained by working in practice alongside conducting this research has made me better as a leader, better as a researcher, and has given me a much deeper perspective from which to draw.

The lesson if there is one, is to do less but not to fear the messy creativity of the mixing of things, people and ideas, and I hope this experience will help me offer others confidence, time, and space to be their best in the future. Inclusive innovation in its truest sense!

This was only ever for one person, my partner in all things, who inspires me daily with her bravery, her boldness, her strength, and her growth (and her ability to use referencing software).

She never gives up. Without her I definitely would have. She taught me how not to.

To Cathy,

You are the brightest light I have ever known.

This is still the beginning, darling.

We have so far to adventure yet.

I love you.

This work is offered in service of, a fairer world.

Contributing Papers

Directly from work in my PhD

Austin, V. and Holloway, C., 2022. Assistive Technology (AT), for What? *Societies* , *12*(6), p. 169. https://doi.org/10.3390/soc12060169

Austin, V., Holloway, C., Ossul Vermehren, I., Dumbuya, A., Barbareschi, G. and Walker, J., 2021. "Give Us the Chance to Be Part of You, We Want Our Voices to Be Heard": Assistive Technology as a Mediator of Participation in (Formal and Informal) Citizenship Activities for Persons with Disabilities Who Are Slum Dwellers in Freetown, Sierra Leone. *International Journal of Environmental Research and Public Health 18*(11), p.5547. https://doi.org/10.3390/ijerph18115547

Setting up AT2030 and the background to my PhD:

Holloway, C., **Austin, V.**, Barbareschi, G., Ramos Barajas, F., Pannell, L., Morgado Ramirez, D., Frost, R., McKinnon, I., Richmond, Lord, Fraser, R., Kett, M., Groce, N., Carew, M., Alghaib, O., Tebbutt, E., Kobayashi, E. and Seghers, F., 2018. Scoping research report on assistive technology on the road for universal assistive technology coverage. https://doi.org/10.13140/RG.2.2.13099.49443

Austin, V. and Holloway, C., 2019. Overcoming systematic global barriers to AT: a new methodology and quickstart testing through a £20m programme, in: GReAT Summit Summary. Presented at the Consultation for the Global Report on Assistive Technology (GReAT), Global Disability Innovation Hub, Geneva, Switzerland.

MacLachlan, M., McVeigh, J., Cooke, M., Ferri, D., Holloway, C., **Austin, V.** and Javadi, D., 2018. Intersections Between Systems Thinking and Market Shaping for Assistive Technology: The SMART (Systems-Market for Assistive and Related Technologies) Thinking Matrix. *International Journal of Environmental Research and Public Health 15*(12), p.2627. https://doi.org/10.3390/ijerph15122627

Additional contributions affiliated with my PhD:

Austin, V., Mattick, K. and Holloway, C., 2021. "This Is the Story of Community Leadership with Political Backing. (PM1)" Critical Junctures in Paralympic Legacy: Framing the London 2012 Disability Inclusion Model for New Global Challenges. *Sustainability 13*(16), p.9253. https://doi.org/10.3390/su13169253

Holloway, C., Morgado Ramirez, D.Z., Bhatnagar, T., Oldfrey, B., Morjaria, P., Moulic, S.G., Ebuenyi, I.D., Barbareschi, G., Meeks, F., Massie, J., Ramos-Barajas, F., McVeigh, J., Keane, K., Torrens, G., Rao, P.V.M., MacLachlan, M., **Austin, V.**, Kattel, R., Metcalf, C.D. and Sujatha, S., 2021. A review of innovation strategies and processes to

improve access to AT: Looking ahead to open innovation ecosystems. *Assistive Technology, 33*(sup1), pp.68–86. https://doi.org/10.1080/10400435.2021.1970653

Albala, S., **Austin, V.**, Holloway, C. and Kattel, R., 2021. New economics of assistive technology: A call for a missions approach. UCL Institute for Innovation and Public Purpose. https://www.ucl.ac.uk/bartlett/public-purpose/publications/2021/jan/new-economics-assistive-technology-call-missions-approach

Albala, S., Holloway, C., MacLachlan, M., Baines, D., Walker, J., **Austin, V.**, Kattel, R. and Mazzucato, M., 2019. Capturing and Creating Value in the Assistive Technologies Landscape through a Mission-Oriented Approach: A New Research and Policy Agenda. AT2030 Working Paper Series, AT2030 Working Paper Series.

Smith, E.M., MacLachlan, M., Ebuenyi, I.D., Holloway, C. and **Austin, V.**, 2021. Developing inclusive and resilient systems: COVID-19 and assistive technology. *Disability & Society, 36*(1), pp.151–154. https://doi.org/10.1080/09687599.2020.1829558

Table of Contents

Abbreviations

AT – Assistive Technology

ATA-C – WHO’s assistive technology capacity assessment

AT Scale – the global partnership on AT

AT2030 – global programme on AT run by GDI hub, funding this work

CCA – Country Capacity Assessment

CHAI – Clinton Health Access Initiative

DPO – Disabled People’s Organisation

GDI Hub – Global Disability Innovation Hub

GoSL – Government of SL

GT – Grounded Theory

FCDO – Foreign and Commonwealth Office UK Aid (previously DFID)

FEDURP – the Federation of the Urban and Rural Poor, SL

GReAT- Global Report on AT; also GReAT summits

I/NGO – International/Non-governmental organisation

MoH – Ministry of Health

rATA – WHO’s Rapid Assessment of Assistive Technology need

SL - Sierra Leone

SLURC – Sierra Leone Urban Research Centre

SLUDI – SL Union on Disability Issues

UN – United Nations

UNICEF – United Nations Children’s Fund

WHO – World Health Organisation

List of Tables

List of Figures

1 Introduction

1.1 The problem this thesis considers, and why?

During the four years of this study, for my ‘day job,’ I visited more than twenty global South countries to design and implement strategic interventions on Assistive Technology (AT). All, in service of; disability innovation for a fairer world, the mission of the social business I co-founded, Global Disability Innovation Hub (GDI Hub). The stories I was anecdotally told reveal an important reality. In 2018, the chairperson of a Disabled People’s Organisation (DPO) in Nairobi told me that disabled children and babies were routinely left outside at night to be eaten by hyenas in rural Kenya; members of the rural community felt this was fair and appropriate. In 2019, a project manager from West Africa told me of her own experience of being treated for a visual impairment with excruciating procedures by a community ‘witch doctor’ (her words), which, of course, did not work; she described it as a common practice and was relieved to recover her vision naturally, as she believed her family were about to reject her. In 2020, the leader of an Indian NGO revealed that she frequently found disabled family members physically tethered inside shelters. This was usual and expected, though horrifying. I saw first-hand a person in significant mental distress shackled in Indonesia on a project visit to an urban settlement. While giving out rice during the pandemic, our project partners in Sierra Leone found many more disabled people than they were aware of, despite having worked in the communities for a year on disability inclusion. These disabled people were never allowed to leave their homes due to the shame and stigma their families felt. These transgressions against the fundamental right to life, participation, being valued and being human are not infrequent, nor are they mild or inconsequential.

Given this context, it feels radical to pose the question: what if we believed that poor, disabled people – especially those living in the Global South - were capable of being the primary agents of change on their own behalf? Can we expect poor, disabled people to lead change for their peers? Could this group be the leaders of change for us all – having experienced the sharpest end of the world as it is currently organised? How would this change our economic plans, our political choices, or donor contributions? These are big questions, and my thesis attempts to provide a stepping-stone toward answering them.

This thesis examines how recent work was designed (loosely) to aid the participation of disabled people via access to AT and addresses some of these issues. It questions which assumptions are built-in and which are not, and through critical analysis centres the views of poor, disabled people themselves - specifically slum dwellers from Freetown, Sierra Leone - to understand how we might do better as a global community together.

I start from what is already known to be true:

> *“Poverty is many things, all of them bad. It is material deprivation and desperation. It is a lack of security and dignity. It is exposure to risk and high costs for thin comforts. It is inequality materialised. It diminishes its victims” (Arjan Appadurai, 2004, p. 64)*.

Appadurai’s portrait of the relational odds stacked against poor people is the grounding for their polemic in support of the hopeful wishing (ibid.). This ‘wishing’ is actioned through slum dwellers' collective practices and recognised as the *Capacity to Aspire* (ibid.). If any single provocation has inspired this investigation, it is through seeing, and not stigmatising, poor, disabled people for who they truly are, and subsequently opening opportunities for the participation of this group, emancipation can begin. This hypothesis is simultaneously born of the belief that the circumstances by which subjugated people find themselves contained are rarely of their own making. Yet - counterintuitively (to some) - their own actions have a necessary and strategic power to spark change.

The cracks of possibility for community-driven freedom are opened when one accepts that, as Sen (1999) argued, it is precisely through becoming the agents of struggle that marginalised people indeed empower and embolden themselves to sow the seeds of their own liberation. This point was emphasised at the start of my PhD journey in the paper on systems strengthening for AT, because agency and participation (by poor, disabled people themselves) should be fundamentally valued in all aspects of an approach to AT provision which aims to be emancipatory:

> *"If agency and participation are fundamental aspects of development as "the ends and the means" (Sen, 1999, p. 35) … then enabling persons with disabilities to participate in society—to speak about their own lives, to shape their families, their communities, the projects that seek to support them, their governments, and research about "them"—is a necessary factor in any development objective"* (MacLachlan et al., 2018, p. 4)

I borrow simplicity here to start with the suggestion - radically in the context of disability - that the seeds of desperation might also be the seeds of aspiration and hope. Most importantly, that leadership must come from poor, disabled people themselves as the primary agents of change, not just the passive recipients of agendas decided elsewhere.

This thesis offers new evidence so we can do better than the status quo, here, to be clear, there are 1.2 billion disabled people worldwide, 90% of whom do not have access to the basic AT they need to participate in daily life activities. The need for AT is predicted to double by 2050, with no alleviation of lack of access expected (WHO, 2018). I suggest in this work that how disability is viewed is also critical to progress on AT access. This idea will be explored in full, but to begin, I borrow again from Appadurai's original opening paragraph to his section on 'Capacity to Aspire' (Appadurai, 2004, p. 64) and take significant licence for adjustment I suggest:

> *Disability is many things, many of them hard. It is societally constructed barriers (physical, attitudinal, structural) and economic, social, and political exclusion. It is a lack of respect, security, representation, and dignity. It is exposure to risk and even higher costs for even thinner comforts. It is ableism materialised. When understood as the interaction between the disabled person and society's choices – it diminishes its victims.*

Living at the intersection between poverty and disability diminishes the *Capacity to Aspire* (ibid.) of poor, disabled people who are subjugated at the hands of society's ableist and exploitative design - perhaps to the most significant degree of any group on our globe today. Yet compared to questions of gender, for instance, very little is discussed, researched, or implemented by way of intervention around disability and poverty. As African authors (Ned et al., 2022) have highlighted , even less is heard from disabled people living in poverty themselves. Their voices are missing. This needs to change.

Having worked in the field of inclusion for more than twenty-five years, I am reminded daily that even colleagues and friends with the very best of intentions usually turn their attention elsewhere. Placating themselves with some version of 'the truth': 'this group is too small to be central'; 'interventions require specialists, it is not my business'; 'work like this presents a distraction from my broader (worthy) aims' (be they development goals for all, or disability equality in the Global North); 'this work is unfashionable/ hard to fund/ too difficult to show impact'; or 'we can tackle this next after we get the basics right. We do not often like to admit the implicitly held belief that fuels this – often subconscious, rarely openly voiced – that disabled people's lives are of less value because they are (sometimes) shorter and of a (subjectively perceived) lower quality. One only has to glance momentarily at the differential impacts (Smith et al., 2021), additional barriers (Smith et al., 2021) and prioritisation of vaccines surrounding COVID-19 to see evidence of this belief in everyday action.

Yet we turn our heads at our peril. For in the fate of the most excluded is not only a dehumanisation and subjugation of lives equal to every other human life on this planet, which most people would struggle to justify if presented with the stark truth, but also, a measure of our values, beliefs about how change happens, understanding of how problems are solved, and implicit assumptions about who can solve the major issues our world faces today. As a case of great complexity, how to support poor, disabled people to live lives *they* value conjures the most difficult of questions. If we care to investigate it, it could also contain the hardest-to-find answers, possibly even with universal impact – though this should not be a prerequisite for interest. Even without broader applicability, there is immense purpose in supporting 1.2 billion people to live meaningful lives. As the launch video for the world's most extensive disability rights campaign – WeThe15 – introduced at the Tokyo Paralympics in 2021, said, "*we're not special – we are just like everyone else*" [and we want to participate]! (*WeThe15*, 2021, p. 15).

If there is a beginning place for this work, then it is here. With an acknowledgement that poverty and disability are, in combination, debilitating, unfair and hard. But this is not the result of some fate of medical biology or happenchance of birth. But instead, this 'hardness' – Appadurai's '*diminished victim*' (Arjun Appadurai, 2004) – results from the choices made every day by others (Wood, 2003), rather than something intrinsic to poor, disabled people themselves. Choices, which enable other, richer people (usually not, but sometimes also, richer disabled people), i.e. the 1% who own more than the other 99% (Oxfam, 2016) to benefit from the unequal distribution of resources but choices too, by some of the 99%, to look the other way. Choices which do not allow the voices of poor disabled people to be heard. Personal, momentary choices, but choices which are forged in the long-term structural, deliberate socio-economic, and political conditions in which they are made. These are both personal and political concerns.

This thesis attempts to consider what ascends from this complexity in uncharted waters. I argue that what arises when we become complicit in the common parlance answers to these difficult questions (simplicity, avoidance and/ or ignorance) is a reinforcement of the current distribution of wealth, power, and participation. Looking away is not inaction but, in fact, part of the reason people remain oppressed. This reinforces the conditions in which poor, disabled people struggle. And looking the other way can mean delivering an AT product and ticking all the donor's boxes while still not enabling participation. This study seeks to offer (and recommend) a more intentional practice: looking more deeply, listening more keenly, and questioning more thoroughly what we think we know and what we have come to accept. In service of nothing more or less than addressing injustice for poor, disabled people.

The theme for this investigation is the role of technology, specifically technology which is assistive to disabled people. This is often called AT, though the definition will be questioned in the coming pages. AT is pertinent because it embodies all that is hopeful about the current paradigm for innovation and much of what is currently on the Donor agenda. But it also represents all that constrains it; usually untethered to any sociological or political framework; often unexplained; sometimes completely unaccountable; with the programmed design often unexplored intellectually or contextually. This thesis reveals that technology is far from an anodyne intervention but subjective and loaded. It does have the power to emancipate its users and the power to reinforce the cages of incarceration. Borrowing an approach from Appadurai again (Arjun Appadurai, 2004) I use his approach to poverty to draft my own contextual description of AT:

> *Assistive Technology is many things, some of them good. It can enable participation and alleviate desperation. It can provide for security and dignity for the (few) people that have it. It has high costs and can provide considerable independence and comfort. It is offered within the system it emanates from, and hence access is currently reflective of, neoliberalism materialized. When provided well, quality AT can enhance the lives of its users significantly.*

In this thesis I adopt Harvey's definition that: "*Neoliberalism is in the first instance a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade"* (Harvey, 2005, p. 2) and I go on to examine AT in this context. My work is an effort to understand better what it would mean to hold space for truly innovative approaches to disability justice, centring the participation of poor disabled people themselves, rather than the aims of a social-economic-political system, or any flavour of government, agency, NGO, or global leader. This might feel challenging to those who are used to holding stable power, money, and resources. I am no exception to this as the leader of the largest global programme on AT – AT2030 – but I have sought to address the data afresh with integrity and honesty, despite the discomfort.

As I will set out in the methodology chapter this work has some limitations – it is naturally imperfect, limited in scope, was hampered by COVID-19 and to some degree constrained by the nature of a PhD study. My hope is that this work will be read as a deliberate effort to listen harder, to hear more, to really think again and to offer recommendations which are pragmatic – for Donors and actors, now. This pragmaticism is honestly situated within a structurally critical analysis of the unquestioned neo-liberal socio-economic and political context, which – I suggest – is part of the problem. A summary of the study context now follows.

1.2 An introduction to the context for this work

Disability is "*complex, dynamic, multi-dimensional and contested*" (World Health Organization and World Bank, 2011, p. 3) with 80% of disabled people living in the Global South (ibid.). Yet, despite the ongoing contestations of 'who counts?' what is no longer in question is the mutually reinforcing nature of disability and poverty as cause and consequence of each other (Braithwaite and Mont, 2009). One thing is for sure; participation by poor disabled people is made harder by lack of access to education (Hersh and Mouroutsou, 2019; World Bank, 2022a), work (Blanck, 2020; Joshi and Thomas, 2020; Lamichhane and Okubo, 2014), affordable medicines (Ebuenyi et al., 2020; World Health Organization and World Bank, 2011), accessible environments (Burton and Mitchell, 2006; Edwards et al., 2001; Steinfeld and Maisel, 2012), and appropriate assistive technology (Desmond et al., 2018; MacLachlan, 2019; Tebbutt et al., 2016). Consequently, this research seeks to investigate the role technology can play in overcoming those barriers, in service of the full participation of disabled people in society.

Building on the **Social Model of Disability (SMD)**, initially published in the mid-1980s (Oliver, 2013) and also taking reflection from Shakespeare's (2013a)evolution of the bio-psycho-social model (BPS), the investigation presented in this thesis considers disability as an *identity* - a way to understand who's who and what's what (Jenkins, 2008)- not a medical concern.

The SMD presents disability as the result of societally constructed barriers (physical, political, economic, or attitudinal) not bodily impairment. The old slogan *"disabled by society, not our bodies"*(Shakespeare and Watson, 2001, p. 11) from the UK disabled people's movement in the 1980s and 1990s summarises this approach well. In the evolved BPS model, disability is understood as constructed by the interaction between function (what an individual's body can do) and attitude and societal barriers (Shakespeare, 2013). In both (SMD and BPS) models, the focus is not allocated to *'fixing'* specific differences in a person's body or mind as *the problem* (e.g., thinking mainly about what a person can or cannot do). Instead, the focus is given to the interaction between a person's function and society[1] (e.g., thinking about how society can adapt to enable all its members to participate independently, equally and with dignity).

Following this logic then, in this study, attention is concentrated on understanding what societal change is needed to enable the poorest people with disability identity to access social, political, and economic justice. Focus is not given to how individuals can be clinically helped or medically supported to function in different bodily ways. For this reason, no clinical assessments were made, and no account was shared of the specifics of individuals' impairments were shared.

The World Health Organisation (WHO) defines AT as products, such as wheelchairs, hearing aids, glasses, walking sticks or digital devices, and the services that sit around them (WHO, 2016). AT is needed by at least a billion people, yet currently, AT is absent for 90% of them;

---

[1] For the lay reader: if a building has stairs, we focus on building a ramp, not fixing, or excluding the wheelchair user – this is the social model, in very simple terms.

there is the need to double its availability by 2050, however no alleviation of shortage is predicted (ibid.). For this reason, WHO and UNICEF are working towards a Global Report on AT (GReAT) to be published in mid-2022. Its delay due to COVID-19 renders the report itself beyond the scope of the study, but much of the background evidence has been reviewed. This seminal report has sought to present new evidence of the need for AT and has introduced new data from many countries, as well as seeking to address the policy recommendations necessary to tackle AT provision globally[2]. The global deficit in AT is a vital and pressing concern since the evidence shows that without action on AT it will not be possible to meet the aims of the set out SDG goals (Tebbutt et al., 2016).

AT2030 is the largest global AT programme set up in 2018 by UK Aid and is run by Global Disability Innovation Hub (GDI Hub) in 34 countries with more than 70 partners. I am co-founder and CEO of GDI Hub and while academic independence has been robustly assured, reflection from practice has occasionally been included to enhance the value and knowledge generated through this study (usually through research diary notes, always indicated as such). Additionally, the study is intended to help build the evidence base of *'what works'* on AT access for AT2030 and was funded by the programme. The possible bias this could introduce has been a constant point of reflection to me as I conducted this PhD and I sought to address possible sources of bias, with my synthesis.

AT, as often argued (eg., Tebbutt et al., 2016) is both a necessary individual requirement for many disabled people and a public good for society at large. This can be an impactful case to build, and many have sought to set out the value of AT in economic development writ large (Albala et al., 2021; MacLachlan et al., 2018; Normie et al., 2001; Savage et al., 2019). This type of economic efficiency argument has been important for attracting funding and resources into this space, including to the AT2020 programme and ATscale partnership. However, beneath this argument can lie a largely uncontested assumption that AT's purpose is to generate engagement in economically useful activity. This assumption has led to the development of return on investment models such as (ATscale, 2020), which contend that there might be as much as a 1:9 return on investment into AT, and that families with access to AT (where it is needed and made available) might see as much as a $100,000-lifetime increase in income. These arguments are helpful contributions, but there is a danger that non-productive activity is seen as less or not valuable at all.

It would be wrong to pretend these business cases have not been useful for those seeking to do more good work by attracting funding into this space, including to me and my organisation. This economic modelling is necessary for the geo-political context of the present epoch and is important in paving the way for more investment, particularly for those who need to make difficult decisions – for instance, governments in resource-poor (post-colonialist) countries like Sierra Leone. However, this kind of economic analysis can also make explicit the assumption that AT is valued where it results in improved economic value, or productivity. This productivism (often used in social protection discussions about disability (Mladenov, 2015a), is also critiqued by those who see disability justice as part of a

---

[2] The Global Report on Assistive Technology (GReAT) was published in 2022 and at the end of this PhD write-up stage and therefore whilst I refer to it and the background papers which were developed for the GReAT report, I do not directly refer to the report as evidence.

broader struggle for social and economic freedom, wellbeing, and justness (Mladenov, 2020). What remains largely unexplored – in the literature and in practice – is the role of AT in supporting more fundamental power shifts necessary to overcome ableism as part of a broader social justice settlement. Thinking that AT might enable disabled people to take collective action on their own behalf, or to seek, and to find, real justice, is intended here.

Disability and AT interventions are usually made without detailed reference to the constraints of **urban poverty** and the very poorest (disabled) people; just as urban poverty work rarely incorporates disability, and hardly ever AT, well (Grech, 2016). Despite a push from WHO to address data collection from the Global South for the Global Report on AT, current evidence is exceptionally poor and patchy (Danemayer et al., 2022, 2021). It is now explicitly documented that as countries lift out of the lowest levels of income (from low to middle-income status) disabled people are left behind (Banks et al., 2017; Groce and Kett, 2013), with poverty being a reality for many, if not most, of the world disabled people who are likely to be AT users (Braithwaite and Mont, 2009).

The 'disability/development nexus' emerged as a field for (arguably, not very broad) debate in the late 1990s following lobbying by disabled people's organisations (DPOs) and International Non-Governmental Organisations (INGOs) with an interest in disability matters (Grech, 2016). Largely located in the human rights based tradition and fuelled by the new UN Convention of the Rights of Persons with Disabilities (CRPD; CRPD, 2006), *'Disability and Development'* does not fit neatly into a single academic discipline and there is a paucity of genuinely interdisciplinary literature and theory (Soldatic and Grech, 2016). Western perspectives still dominate the discourse with limited relevance to poor disabled people in the Global South (Chataika and Mckenzie, 2016) and definitions of disability (Oliver, 2013; Shakespeare, 2013) are often based on Western analysis or excluded from mainstream thinking about urban poverty. This is also true of theories of justice.

Theories of justice are potentially even more loaded and contested than those around disability and hence attention to what disability justice means is given considerable reflection in this study as the fourth dimension. Reviewing the theoretical foundations of justice from a disability perspective, as well as contemporary applications in practice, I settle on Fraser's framework of *Parity of Participation* (Fraser, 2000) as the most useful approximation and use it, in combination with the work of Sins Invalid (Berne et al., 2018) a social movement on disability justice, as a framework and organising principle for the later empirical chapters. This frame was chosen because it recognises the value of *redistribution* alongside *recognition* and *representation* as part of a paradigm which proposes a realignment of theory. I combine this with *disability relations* – to catch the disability-specific elements related to radical inclusion, solidarity, and intersectionality.

From these dimensions - disability, AT, urban poverty and justice – I situate this study, setting out a framework in Chapter 3. This work draws on a case study in West Africa.

1.3 The focus of the study: Freetown, Sierra Leone

The study is explored through the primary lens of disabled slum-dwellers in Freetown, Sierra Leone (SL). The core participants live in informal settlements in the city; two mainstream settlements with mostly non-disabled families and one autonomously run settlement dedicated to disabled people and their families. Sierra Leone is a small coastal country in West Africa and one of the poorest in the world, ranking 180/186 (Berghs, 2012), with 90%

of people living under the higher-income poverty line of $6.85/day (World Bank, 2022b). According to a 2015 survey (Statistics SL, 2017), SL is home to approximately seven million people, and life expectancy at birth is 48. Access to livelihoods is particularly challenging, and approximately 70% of youth are unemployed (ibid.), with only 3% of disabled people in employment(Statistics SL, 2017). World Bank reports show COVID-19 has made the economic situation even harder (World Bank, 2022b)

As chapter 5 highlights, SL has suffered colonial rule through direct control from London until 1961, subsequent corruption leading to a bloody and protracted Civil War (1991-2002), and finally, the Ebola crisis (2014-16). Comparatively, at the time of writing (early 2022), the country is now in relative harmony despite the impacts of the COVID-19 pandemic. It remains rich in natural resources (despite their historic extrication), has a temperate, tropical climate, and is stunningly beautiful – all of which have increased international investment now during relative stability. This will soon include a Donor-funded new route to the airport, cutting the 4-hour drive to the mainland, which is perceived to put off investors. About a third of the population lives in urban areas, and Freetown City Council is led by a progressive Mayor, Yvonne Aki-Sawyer, who is addressing infrastructure and transport concerns and recognises that slum dwellers are an important constituency. The Mayor of Freetown included consideration of, and priorities for, disabled people in 'Transform Freetown', the Development Plan for Freetown (Freetown City Council, 2019)

Disability itself is an evolving concept in the country constructed through the lens of the legacy of sickness (Walsh and Johnson, 2018) and war (Berghs, 2012). The government has a relatively robust legislative framework, yet insufficient data, and underestimates in official statistics which put the total of disabled people at fewer than 100,000 people (Statistics SL, 2017). Sadly, the policies still need to be implemented in many cases. Freetown, SL was chosen due to the strong and long-term relationship between UCL and the Sierra Leone Urban Research Centre (SLURC) and the access it enables. Given the desire to have challenging and meaningful discussions with usually hidden communities within the settlements that were connected to a strategy for claims-making, this was vital. This PhD study was conducted as part of a wider AT2030 programme as explained in chapter 4.

1.4 Scope, Methods and Contribution

1.4.1 Scope

Reflecting on the complexity, this study seeks to consider at the intersection between disability, urban poverty, technology and justice, the following research objectives were designed:

- To develop an understanding of the role of AT in supporting poor disabled people's claims;
- To explore the role of AT, grounded in the context of those living in low-resource settings, and what else matters;
- To inform policy debate and practice at the local, national, and international level.

These objectives inform the core research question:

How does access to AT mediate recourse to disability justice (DJ) for urban poor people?

The overarching research question is answered in this study in relation to sub-questions:

- **What is this situation in relation to AT access globally, nationally, and locally? What definition of AT is the best fit for the data**?

This first research question is answered in the first empirical chapter (6). In chapter six, first data from local, national, and international levels is presented, which sets up the chapter's deep dive into the discussion of what AT is. Then a discussion of what is missing from the settled global AT definitions follows, and a new approach is presented in the conclusion to the chapter.

The next sub-question is then considered:

- **What are the dominant understandings of DJ globally, locally, and nationally? What are the main claims for DJ of urban poor people in the study?**

This second research question is answered in the second empirical chapter (7). In this chapter, firstly interpretations of disability justice are considered at each geographical level before a deeper consideration of what justice means to poor disabled people is presented in the second part of the chapter. Here, I use the framework I set out in chapter 3 to organise the data according to representation, recognition, redistribution, and disability relations. The chapter concludes with a discussion of wider justice claims.

The next sub-question is then considered:

- **What is the relationship between AT and DJ for urban poor disabled people in the study?**

The third empirical chapter (8) relates to the third research question which considers the dynamics between AT and justice. Again, in chapter eight, my framework is employed as a frame for the data, and again the lived experience of poor disabled people in Freetown is centred with some national and international context woven in. The chapter considers the dynamic relationship between AT and DJ for urban poor people.

A framework for the study has been developed and is set out in Chapter 3, this is reproduced below:

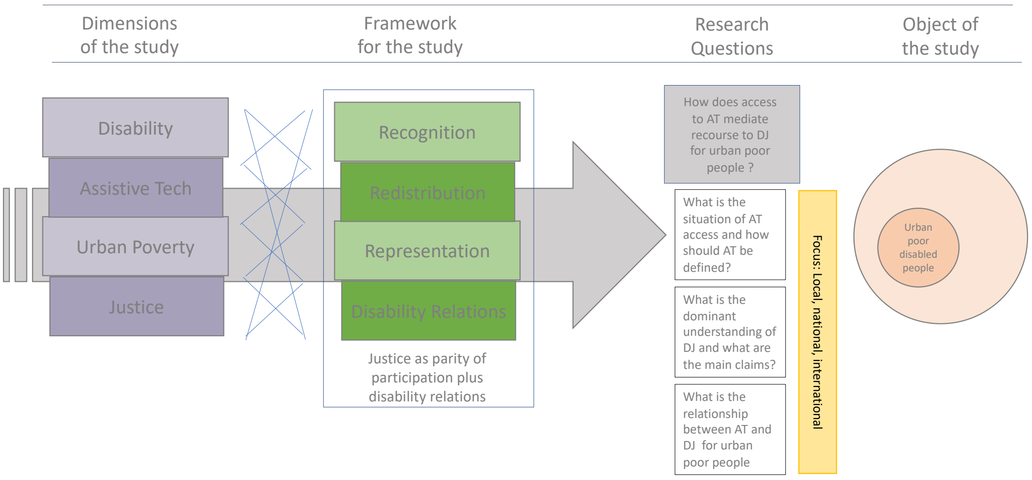


Figure 1: Framework for the study

1.4.2 Methods

This thesis uses qualitative methods across six datasets over four years. As chapter 4 sets out, the methodology was adapted due to COVID-19, to include a set of remote interviews with global leaders on disability and AT. This enabled more global contextualisation and addressed the prevention of travel in the middle of the fieldwork years. It was also necessary to complete the final interviews with participants in SL online.

The resulting data sets are six, A-F, which were collected between June 2018 and November 2021. Across these datasets, the following methods were used: interviews, focus group discussion, event observation, a survey, policy review, and field notes. Thematic analysis (Braun and Clarke, 2006) was used to draw out themes from the local datasets first, which were published in an initial paper (Austin et al., 2021a). Some datasets were shared with researchers within this project under the direction of the project principal investigator. I conducted 36 interviews myself and supported four events directly. I commissioned or contributed to national and international studies and contributed to conferences and summits both at WHO in Geneva and in Sierra Leone. I also participated in setting the objectives and initial research intention of the AT2030 sub-project led by the Development Planning Unit at UCL, attended much of the part 1 research programme, and have reinvestigated this data for this thesis. From these activities, I have included some of my own field notes in the empirical chapters, where these were critical to my evolving thinking. As CEO of GDI Hub, which runs AT2030, I have kept a daily diary since the programme began. Naturally, I have not shared confidential information or named individuals from the notes.

All research methods have been ethically approved by UCL and this research contributes to the overarching AT2030 ‘data and evidence’ cluster of projects investigating the overarching research question *“What works to get AT to the people that need it around the world?”.* The fees for this PhD were paid to UCL by AT2030 (UK Aid), and no stipend was taken.

1.4.3 Theoretical contribution

This work explicitly furthers the understanding of AT in the context of urban poverty. The research ‘talks back’ to the literature on the nexus between disability studies - assistive (and accessible and emancipatory) technology, inclusive urban development (from the Global South perspective), and (disability) justice. Given the paucity of data, and especially the lack of data which elevates the voices of poor, disabled people themselves (Ned et al., 2022), in principle, this research sets out to contribute to knowledge about the lived experience of poor, disabled people. This work should be read as an active attempt to develop research which can provide for ‘social justice through pedagogy’ (Goodley, 2007). Reference to practice is essential, too, as the lag of getting innovative product/ service model trials written into literature is significant, and this field has expanded exponentially since 2018.

The thesis argues that the disconnect between access to AT and any solid framework of disability justice enables a nascent ‘why?’ of AT to emerge, or a series of normative ‘whys’? adopted by actors who wish to further, for instance productivity, rather than something more broad ranging, like ‘the things disabled people value’ following the Human Development Paradigm (Sen, 1999). Setting AT within a frame of access to disability justice for the poorest people appears to be as vital and missing as AT. At the same time, AT is a critical enabler and an essential claim of disability justice. Following Sen's (Sen, 1998) seminal lecture *Equality of What?* the thesis asks the question: *AT for what?* and attempts to illuminate the beginnings of an answer, which is: for disability justice comprises of four elements: representation, recognition, redistribution, and positive disability relations.

1.4.4 Findings

This study finds that quality AT is missing for almost all poor, disabled people, and its lack is most apparent for those living in mainstream urban settlements where disability invisibility, stigma and a lack of recourse to the power of collective action are present. It finds that disabled slum dwellers living in autonomously organised disability-led urban settlements appear to have much greater access to AT, suggesting a further investigation into the role of collective action and autonomous organising would be fruitful. The study also finds that AT is a necessary factor in the participation of poor, disabled people and that this participation is greatly valued.

The work reveals that globally, AT interventions are not organised under a common operational framework for intervention; hence, '*AT for what?*' becomes a pertinent point given this lack of consensus. This operational framework is pressing, and vital as new actors enter and what we term assistive products proliferate. Of course, the data suggests that AT alone is not enough to facilitate justice. Still, its provision within a more robust framework of DJ would better serve the needs and aspirations of urban poor, disabled people. The work offers some initial shape to that framework.

Further, the study finds that the claims for DJ for poor, disabled people are often subjugated to background conditions, sitting behind the life-and-death claims for the basic need of life (water, shelter and/ or food). Hence any framework for DJ must be linked to a broader push for justice for all poor people to be meaningful and impactful. The study concludes that any general social justice movement must place DJ within its heart. Additionally, it also makes the case that AT is more than a commonplace element of that struggle. Due to its fundamental necessity in enabling participation, I suggest that AT can be viewed as a *transitional demand* for DJ.

1.5 Limitations and Exclusions

The focus of this work is on low-income communities. AT availability still needs to be improved for higher-income groups in many contexts. However, here the overlapping nature of disability and poverty in the context of urban informality is the intended site of exploration.

For newcomers to the field of disability, and for the avoidance of doubt, this is not a study about individual impairments and the efficacy of any assistive products or services. Nor does it delve into the disaggregation of data by impairment - this is because disability in this context is viewed as a social, relational identity experienced through individuals' holistic experiences, not a medical diagnosis or condition. No clinical observation was taken, nor will it be offered. Nor is this an assessment of the effectiveness of technologies in context. Both are for others, and for elsewhere.

Similarly, the concern of AT for older people is vital to the global AT agenda and policy consequences, but it is not the focus of this work. The societal, political, and economic context is very different for older people; the nature of the formulation of identity is different too, and it would not have been meaningful in the scope of this work to consider the two in a simple combination. That is not to say none of the participants were older; some were, but their experience was considered under the frame of disability, not age identity. These exclusions have cleared space for deep thinking that is ‘on topic and in scope’. The life experiences of poor, disabled people often go unexplored as they are crowded out by a focus on one or more of the points of exclusion above, so this is entirely intentional.

Finally, as chapter 3 details, COVID-19 limited the participatory nature of this work and rendered the second phase of research virtual; its challenges I have mitigated as much as possible. No doubt the result would have been more participatory if I had been able to return to SL post-2020. However, there are also unintended positive consequences in building the local capacity of research organisations to support remote work. Virtual work gave a chance to bring in a new dataset (international experts), enhancing the work considerably.

1.6 Navigating the document

To aid the navigation of this document, I have prepared the following thesis map diagram, Figure 2, which represents the logical journey of the reader. The map shows this chapter setting the scene, followed by chapter 2, the literature review, which covers four distinct but ultimately overlapping domains. In summary, it seeks to present the salient topics exposing their overlaps and challenges by way of a launchpad for the following empirical investigation. Section 2.1 recognises the many constructions of disability, 2.2 summarises the literature on AT, 2.3 considers the nexus of disability, citizenship, and urban poverty; and 2.4 presents theoretical perspectives on justice.

The theoretical perspectives critically reviewed in Chapter 2 lead to the theoretical framework set out in Chapter 3, which guides the analysis in the rest of the investigation. This framework provides the organising principles for the data and presents a theory of DJ which builds upon the principles of the social model of disability, a relational approach to poverty, and priority products plus services definition of AT used by the WHO, and combines Fraser’s parity of participation theory of justice (Fraser, 2008) with an extension to encompass the points above and the Sin Invalids’ (Berne et al., 2018) framework for DJ.

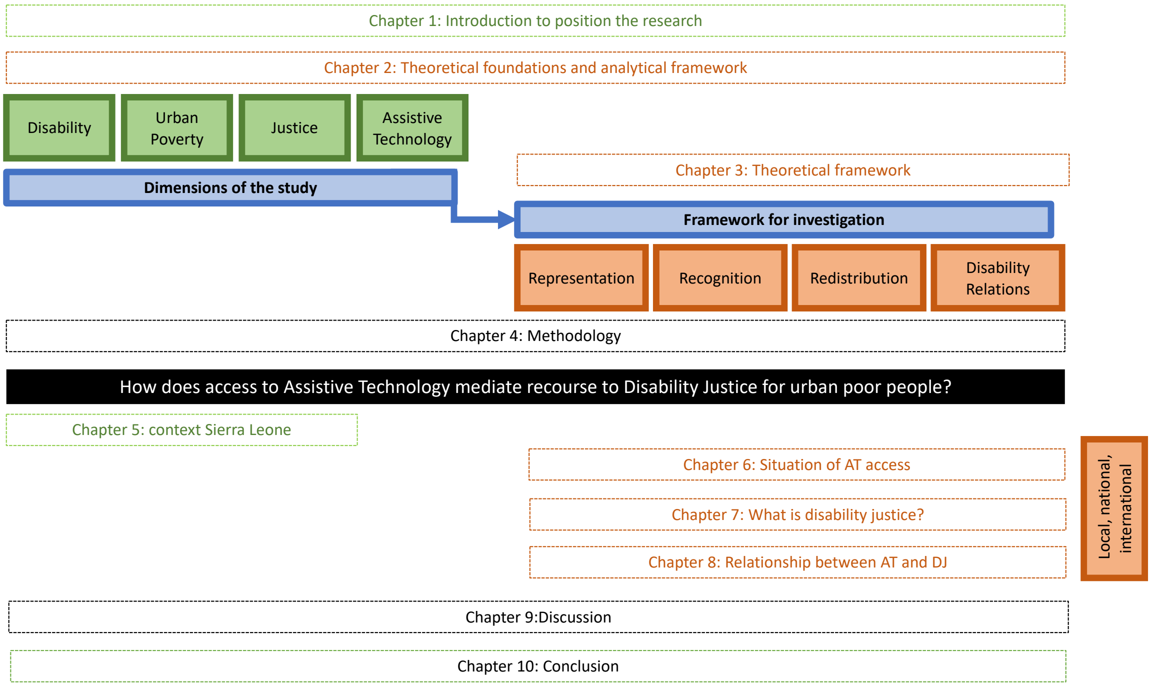


Figure 2: Thesis Map

Chapter 4 then explains the methodology employed, and Chapter 5 presents the background of Sierra Leone.

Chapters 6-8 are devoted to the empirical findings. Evidence is presented first about AT (in Chapter 6), considering access at each geographical level – international, national, local - then questioning the definition of AT. DJ is explored in the second empirical chapter (in Chapter 7). First, common understandings are presented - at the international, national, and local levels – then, using the framework, I investigate the claims for justice of disabled slum dwellers in SL. The final empirical chapter is given over to the dynamics between the AT and DJ (in Chapter 8), again using the representation, recognition and redistribution frame of justice to consider the role of AT in DJ**.**

Chapter 9 summarises the findings presented in the previous chapters and draws out the discussion placing it back into the context of existing research. Finally, Chapter 10 concludes the thesis and provides a summary.

This work is offered in service of academia and progressive, evidence-based action facilitating more robust routes to justice for the poorest disabled people.

2 Literature Review

2.1 Introduction

This chapter presents a review of the literature relevant to this thesis, situated as it is in the nexus between disability studies, assistive (and accessible and emancipatory) technology, inclusive urban development from the Global South perspective, and (disability) justice. The review seeks to present the salient topics, exposing their overlaps and challenges by way of a launchpad for the following empirical investigation. It is presented in four distinct but ultimately overlapping sections.

First, I consider how disability itself is constructed (in 2.2), and this section of the review presents the prominent paradigms with historical distinctions and explores some of the applications in practice. I also map where possible to the congruent themes of social development theory, anticipating the debate to come. The resulting understanding of disability presented here is naturally political, contested, collective and congruent with an account which values social relations, geographical context, societal construction and psychological realities as well as physical impairment, largely borrowing the principles of the **Social Model of Disability** (Oliver, 2013). The key themes are again summarised at the end to be picked up in the framework chapter (3).

This leads to a second discussion (in 2.3) about access to AT. Debates about how AT is defined are presented here at the outset, before adopting the understanding of AT used by the WHO (WHO, 2016); **AT is the provision of products plus services** needed to enable their safe use. Then, I present the global policy positions in this area of work, which is gathering significant momentum ahead of the publication of the first AT Global Report in 2022. This is followed by a summary of current research drawing heavily on grey as well as academic literature, ordered against the themes of the Global Assistive Technology Strategy, set out by the global partnership on AT, (ATscale, 2019). This deep dive into literature alongside policy and practice is necessary to make this summary current and to avoid being limited to the vast array of literature focusing on individual technologies (mainly their clinical efficacy), or individual impairments (following the medical model of disability winch I have discounted in 2.2) - these are out of scope of this work, given the construction of disability adopted. What is presented stays tight to the study of AT within the context of supporting disability inclusion in a collective sense, as well as enabling space for a summary discussion of the role of accessible mainstream technology. Accessible mainstream technology (e.g., automated captions available in Zoom, Google/Microsoft workspaces) is increasingly being used in place of traditional AT and these themes prove relevant in the later discussion. Finally, a discussion of technology which is engaged by social movements is touched upon. This section closes with a critique of ‘tech optimism’ giving rise to several points of dissensus to which this research will return in discussion and conclusion. Again, summary thematic points are presented at the end of the chapter, to inform the framework.

Next, disability within the context of urban poverty forms the third sub-section (2.4). First, the context of urban poverty and disability is presented, with a section added on the broader health issues around urban information. This leads to an initial discussion of how poverty is defined, and the relevance of power and agency to this debate, considering the specific case of the non-autonomous agency. Next, models of citizenship are considered, and their relevance to the topic in hand is critically questioned in so far as they take account of disability and whether the notion of 'citizenship' presented has meaning from the perspective of disabled people living in the Global South. This surfaces a distinct lack of evidence and data, particularly regarding the voices and accounts of poor, disabled people themselves. Often, as shall be revealed, a gap emerges in the nexus between urban poverty in the Global South context, disability, and technology, indicating where this work can 'speak back' to the literature. The following section returns to the discussion about issues of agency and power relations which emerge as significant from the critical review of citizenship considering how a **relational understanding of poverty** can begin to speak of disability. A concluding section provides the key points/ ideas and themes for the framework construction.

The next section of the review (2.5) focuses on the interconnection between disability and justice. Drawing upon the dominant models of justice and applying the same principle of tight scope as before, the most meaningful propositions about *who*, *where* and *what* counts in justice are critically appraised from the disability perspective. The final part of this sub-section pulls back, drawing principles from the justice literature and making the connection to the new and emerging work on DJ only recently published by (primarily) social movements. This current perspective on DJ focuses the lens for investigation with more clarity – offering an intersectional focus which emphasises interconnected solidarity. Here, I consider the merit of **'marrying' the long-standing theoretical justice position of Frasers'** ***Participatory Parity*** **(Fraser, 2005) with the new firebrand activist approach of** ***Sins Invalid Disability Justice Principles*** (Berne et al., 2018). The chapter closes (in 2.6) with reflections on what has come before and a presentation of emerging ideas for the conceptual enclosure of the study to come to be picked up in the framework chapter next (chapter 3).

No study of disability can begin without recognition of the paucity of data. Some of the themes of this investigation emerge as gaps, shown in relief of where the evidence should be: disability and collective action, the connection between disability and struggles against urban poverty, and disability, identity and stigma in the Global South context. Many of these under-researched areas lack most the voices of urban poor disabled people themselves whose potential to tell their own stories is mired by their day-to-day struggles for the basic means of life, and indeed a lack of the technology through which participation can be enabled. It is the gap I intend this work to speak to.

2.2 Constructing Disability

2.2.1 Entering the literature on disability

Defined differently across disciplines, interest groups and practice, "*disability is increasingly salient as a word and increasingly heterogeneous as a category*" (Grue, 2017, p. 168). The debates about disability – as with any contested notion of its type - are necessarily political (Oliver, 2013), relational (Thomas, 2005) and ontological (Mladenov, 2015b), and hence to keep scope tight, a summary is presented below, constantly holding the question in mind: *what is necessary information for this work*?

Before we begin:

For some readers, disability will be a new topic. Thus, it should be considered that, like gender, disability encompasses a large group of more than a fifth of the world, but disability is not uniformly experienced. Instead, the experience is contextually defined. Similarly, though they are salient themes, not all work on disability will address physical access in the built environment, clinical interventions, or care, though these might be the first things to come to mind of the non-expert. These topics are largely out of scope for this research unless they enable a better understanding of the focus on technology as it aids justice. Gender investigations will not always pick up childcare issues, nor can disability investigations all discuss accessibility, care, or clinical matters. Forgive me if this point is slightly laboured, for the question has been repeatedly raised.

2.2.2 Disability in a Global Context

Disability is a significant development concern for those interested in the Global South in scale (the number of people it affects) and scope (what it demands we consider). Yet, a dearth of evidence on which to base policy was one incentive for the World Health Organisation and the World Bank to combine forces to produce the seminal World Report on Disability (WRD) only as recently as 2011. It suggests that approximately 1 billion disabled people in the world, 80% of who live in the Global South, use snap-shot proxy indicators to make this estimate. The figures have not been updated since (World Health Organization and World Bank, 2011). The WRD is a comprehensive and pivotal document with echoes of the way the first Human Development Report in 1990 (Fukuda-Parr, 2003) changed both the debate and practice. The late Professor Stephen Hawkins' forward stated:

> *"It is my hope that beginning with the Convention on the Rights of Persons with Disabilities, and now with the publication of the World Report on Disability, this century will mark a turning point for inclusion of people with disabilities in the lives of their societies".* (World Health Organization and World Bank, 2011, p. 3)

However, while Fukada-Parr and Sen intentionally set out to change the focus on development economics from national income accounting to human centered development approaches (United Nations, 1990), the WRD offers slightly less clarity on approach and is (arguably) less ambitious since it seeks to describe the current data and evidence, rather than set a new paradigm for global development terms. Nonetheless, most commentators agree it was still a vital milestone. It is worth noting that I am aware, through my work, that discussions continue among the International Disability Alliance (IDA) and others about a refreshed WRD, with less focus on health (and therefore without leadership by WHO). Notwithstanding the need for progress, WR changed the game. As Bickenbach summarised:

> *"The World Report on Disability (WRD), launched on 9 June 2011 at the United Nations Building in New York, is an astonishing achievement – not because it singlehandedly shifts paradigms, makes utterly novel recommendations or raises issues never before considered by people with disabilities: its achievement is that it is fastidious about evidence, conscious of the reliability of its assertions and recommendations, and transparent about the enormous gaps that exist in evidence about disability, especially in low and medium resource countries of the world."(Bickenbach, 2011, p. 654)*

To supplement the World Report on Disability, the WHO is currently also producing a Global Report on Assistive Technology (GReAT) and estimates that there will be up to two billion people who will need access to AT (like walking sticks, wheelchairs or hearing aids) by 2050, and that currently 90% of people do not have access to it (WHO, 2016). This will be presented in detail in the following sub-section of the literature review.

There is no global estimate of the number of disabled people likely to live by 2050. Still, the assumption about technology use indicates of the size of the group who might be affected by impairments in the future (whether or not they count themselves as disabled people). While this thesis focuses on disabled people of any age, it is essential to recognise that a person's disability status does not remain constant. It changes over a lifetime and is relational (to the rest of the population they live with) and contextual (to the environment they live in). Almost everyone's family will experience disability, in one way or another, at some point - most of us have this experience in our families right now. Those of us lucky enough to get older will surely have personal experience of impairment. As the recent campaign launch for an extensive global disability inclusion campaign, which reached 4.5billion people during the Paralympics in Tokyo, WeThe15, stated: Disability is 'everyone, everywhere…Disability is humanity.' (*WeThe15*, 2021)

Despite the debates, and however one chooses to measure development progress - which is hugely contested in itself, one thing is agreed upon; disabled people are amongst the poorest of the poor no matter what evidence base is used. Disabled people

> *"…have far less education than others in their societies, fewer savings, less paid work and less involvement in community affairs. [They] are among the most excluded, the most disadvantaged and the most without voice"* (Baylies, 2002, p. 727).

As the WRD states:

> *"Many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life they need, and experience exclusion from daily activities. …Disability is also an important development issue, with an increasing body of evidence showing that persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities* (World Health Organization and World Bank, 2011, p. xxi).

A second vital piece of the jigsaw is the legal framework, which I will now consider.

2.2.2.1 The Convention on the Rights of Persons with Disabilities, 2006

The Convention on the Rights of Persons with Disabilities (CRPD) was approved by the UN in 2006 (United Nations, 2006). Article 1 of the CRPD explains the complexity of disability and its relationship to societal barriers:

> *"(P)ersons with disabilities include those with 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….Consequently, the notion of "disability" is not fixed and can. It can alter, depending on the prevailing environment from society to society, and disability is not considered a medical condition, but by dismantling attitudinal and environmental… 'persons' can participate as active members of society and enjoy the full range of their rights. …The Convention does not restrict coverage to particular 'persons';*

> *rather, the Convention identifies persons with long-term physical, mental, intellectual and sensory disabilities as beneficiaries under the Convention* (United Nations, 2006).

The CRPD is a hard-won (primarily by DPOs) and an essential piece of the infrastructure for disability inclusion; it is a necessary factor in liberation, and an important global human rights instrument: in both practical (bringing together a single statement of human rights for persons with disabilities), and symbolic (the political will it generates from signing up and subsequent reporting, however weak) terms is a valid tool of change. As Asha Hans highlights, this global disability human rights treaty was envisioned by many as a new world order (Hans, 2006). However, in common with most UN Treaties, while it has a role to play in global advocacy and civil society mobilisation, for those in the poorest settings, it is often only as useful as its local implementation.

In practice, the protection it provides can be extremely limited. As a global convention, it must be nationally legislated to enable recourse to justice to be meaningful for citizens. When it is, its intention is often watered down or its content lost; regular reporting frameworks to the UN are weak and inconsistent; national recourse to justice can be mediated by money or power and influence; and policy implementation at a local level, especially for those living outside of formal structures of governance (e.g. slum dwellers) is understood to be weak and difficult to track.

In short, recourse to justice under the CRPD is slow, expensive, and far removed from lived realities of most poor disabled people. The CRPD itself is also still only signed by 163 countries, with 92 in-county ratifications. Hence, it is perhaps necessary, but certainly not sufficient, to generate improved wellbeing for disabled people; this would require a global programme of action and local implementation for the legal rights alone to be a congruent reality for most disabled people. That said, it is a milestone, and a necessary factor in the process of emancipation – albeit it is not a sufficient one.

2.2.2.2 A Human Rights Based approach to disability and development led by the UN

Building out from the CRPD, Human Rights have become one of the key concepts in disability in recent years, including in the disability and development discourse, though there are challenges in operationalising the approach in practice (Katsui and Kumpuvuori, 2008), as we shall see the empirical data reflects this.

The CRPD did not enshrine new rights, but rather it gathered together existing human rights and placed them in a single location, with associated political profile and the commitment, garnered at the very highest level as conventions do it, shifted the debate. Each year signatories (or States Parties) meet at a convention (called CoSP) in New York, and review progress alongside NGOs. Loosely this becomes the global conference on disability. Yet, unlike *UN Women*, the UN system does not resource a similar comprehensive disability section.

Rather, *UN enable* is the alternative and is extremely small in size and resources. The UN Partnership on the Rights of Persons with Disabilities (UNPRPD) is similarly small. While both are occasionally mighty in setting strategies and trialling bold approaches, their collective role is largely advocacy, with a tiny amount of programming and some coordination. Any significant targeted disability budget sits inside the multi-lateral and bi-lateral agencies – with UNICEF, WHO, FCDO, USAID and NORAD taking the most prominent roles. It is often not the disability sections that have budgets to invest (which tend to lead policy rather than the programming of such organisations). This often means disability programming is designed by non-specialists and the targeted programmes are literally tiny.

One recent attempt to address the need for more joined-up action, which provides some cross-agency coordination intention, is a new **UN Disability Inclusion Strategy** (United Nations, 2019) which recommended a 'twin track approach' integrating disability-specific initiatives balanced with mainstreaming (Ibid.). In practice, this is, without doubt, a strong approach. Clearly, lessons are attempting to be learned here from the long *'Women in Development'* history, which built on a very focused targeted approach to encompass a broader range of mainstreaming issues through its transition to *'Gender and Development'*. The key point to take from this is the 'twin track' approach: targeting plus mainstream inclusion. Yet, the fact remains blatant: UN policies and treaties offer very little in terms of direct recourse to justice for individual disabled people experiencing injustice in their country context. Without local legislation and the means to access the provisions in the strategies, treaties, and policies, even legalistically viewed, justice is often out of reach. This is partially the reason why I explore justice in its complexity beyond just the legal or human rights positioning. The Human Rights model of the UN, however, has its role to play, and sits alongside, rather than in competition with, more local responses. Activists refer to it often, and it adds to their advocacy. One element of the UN programme that does set out strategic operational (arguably) work, which is better accounted for, is the Global Goals.

2.2.2.3 Global Development Goals

The Millennium Development Goals (MDGs) failed to take account of disability at all in any significant way, despite picking up other social justice concerns (Groce and Trani, 2011). Grech argued that opposition to this can be viewed as the catalyst around which social movements were able to organise and noted that *'inspired by gender mainstreaming many took this lobbying very seriously, calling for what they framed as 'disability mainstreaming'*, thus promoting the idea that disability needed to be infused within all aspects and processes of development' (Grech, 2016, p. 5).

In 2015, the new Sustainable Development Goals (SDGs) (United Nations Development Programme, 2016) did finally recognise disability for the first time, with a commitment to *'leave no one behind'* and a number of indicators on disability which cut across the 17 high level Goals (Puthenkalam, 2016). This offered, at last, the global framework on which to 'hook' disability and development work - the cracks through which to enter the arena (Frediani, 2010). However, evidence of action is slow and accountability poor, with reliance on proxy indicators.

Professor Nora Groce of the Global Disability and Development centre at UCL, argued at a UN High Level Meeting in 2017, that the UN had never *"considered any group with any greater need or greater potential [than disabled people]"* suggesting *"action was now vital"*, for the first time could be effective (due to a 'significant shift in knowledge insight and experiences' mainly since the CRPD) and would be efficient due to new methodologies which allow for collection of disaggregated disability data (Groce, 2017). By 2021 still there are calls for better accountability on disability, with COSP 2020 being focused on "A decade of action and delivery for inclusive sustainable development: implementing the CRPD and the 2030 Agenda for all persons with disabilities" concluding there was much work still to do (United Nations, 2021).

2.2.2.4 Disability and Development Emerging as a Sector

Despite the high-level framework of the SDGs from which to launch vital, effective, and efficient disability development action 'disability and development' is not a singular but are dual, dynamic, contested, sometimes competing, overlapping concepts, each with their own challenges and limitations. The 'disability/ development nexus' emerged as a field for (arguably, not very broad) debate in the late 1990s following lobbying by disabled people's organisations (DPOs) and International Non-Governmental Organisations (INGOs) with an interest in disability matters (Grech, 2016). Largely located in the Rights Based tradition (fuelled by the CRPD), *Disability and Development* does not fit neatly into a single academic discipline, and there is a paucity of genuinely interdisciplinary literature and theory (Soldatic and Grech, 2016). Western perspectives still dominate the discourse with limited relevance to poor disabled people in the Global South (Chataika and Mckenzie, 2016) especially since definitions of disability are hugely contested and often based on this Western analysis (Shakespeare, 2013).

The WRD presented evidence to suggest that disability is both a 'cause and consequence' of poverty, building on earlier work (Braithwaite and Mont, 2009). This is because poor people are more likely to experience impairments (due to lack of access to healthcare, preventative public health measures like running water) but also disabled people are more likely to live in conditions of precarity (Harris and Scully, 2015; Pendall et al., 2012; Price and Goyal, 2016) and to be poorer (due in no small part to the added cost of living with impairments). What's more, at a macro level, there is evidence of a 'disability and development gap' showing disabled women and men fare less well than other poor people as countries move towards middle income status, in part due to being 'left behind' as incomes rise (Groce and Kett, 2013). Despite knowledge of this, many interventions fail to break the "complex and nuanced feedback cycle between disability and poverty" (ibid., p. 8); lacking explicit normative frameworks (or theories of change), avoiding or obscuring positionality, and failing to involve disabled people in the policymaking and programme-design-evaluation process are commonplace and lead to less good outcomes and reinforcement of the existing power structures which subjugate disabled people (ibid.).

2.2.2.5 Summary

As the CRPD acknowledges, disability is an evolving concept which *"results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation"* (United Nations, 2006, p. x). This consensus is often most easily found in acceptance of this complexity with some degree of focus usually attributed to the combination of social and environmental factors and a person's own characteristics which result in commonly experienced barriers to taking part in everyday activities. As we shall come on to discuss, this has strong linkages with our understanding of justice, both in terms of rights, in participation and in practice. Firstly though, an understanding of the historical models that led us to this broad consensus is essential.

2.2.3 The Medical Model of Disability

Historically, disability was understood through the 'medical model' (Oliver, 1994) with the focus on how to 'fix' the person with the impairment. The medical understanding of what is 'wrong' with a person, centres on the individual, with the associated responsibility for living with any barriers to participation resting on the individual, under the instruction of their medical practitioner, perhaps with paternalistic charity of 'help' often based on pity for the individual in the 'sorry' situation. In this model, barriers to participation were simply accepted by the clinicians, social or charity workers making the decisions, as bad luck for that person. Rather than offering challenge, the barriers were perceived as individual and not understood as structurally or societally constructed.

Naturally then, interventions which were guided by the medical model often focused on strengthening clinical interventions. Building individual agency and autonomy are not key principles of this approach. Sympathetic charity interventions were often linked to religions or religious organisations and have a long history of entanglement with the medical approach to disability. As Shakespeare noted:

> *"The ethos of charity—understood as dana in Buddhism and Hinduism, tzedakah in Judaism, and zakat in Islam—has enabled some disabled people to find support and comfort. But traditional scriptures also describe impairment in terms of uncleanliness (Leviticus 21:16-23) or view problems in terms of possession by devils (Matthew 12:22 and Mark 5:2-20). Some scriptures also imply that a person is disabled as a punishment for their own sin or that of their parents (Exodus 20:5 and Matthew 9:2" (Shakespeare, 2014)*.

In many global south contexts, it is still the case that services accessible to disabled people are delivered by organisations operating within the medical model, provided by charities or sometimes the state. In fact, disability is often still viewed as *'an act of god'* (Retief and Letšosa, 2018), and some believe that particular impairments are the result of a failure to observe social, religious or moral 'norms' either by the person or their family (Henderson and Bryan, 2011).

For many disabled people, the notion of being seen as 'abnormal', 'immoral' and needing to be 'fixed' is still commonplace. Yet, this is tantamount to the shaming of bodies that are different, and even the most well-intentioned interventions starting from this viewpoint reinforce power dynamics, a lack of agency for disabled people themselves, and exclusion - often literal exclusion in homes for 'The Disabled'(sic). For these reasons, the medical model was heavily criticised by Disabled People's Organisations (DPOs) as they grew up, and in the Global North the Social Model of Disability (SMD) emerged in response (Oliver, 2013).

2.2.4 Social Model of Disability

Similar to feminist interests, Oliver argued that 'the personal is political' (Oliver, 2007) in disability terms too. The SMD was described by its author as a 'tool for action' rather than a theory (Slorach, 2011). It was launched alongside a movement spreading under slogans like "*nothing about us without us"* and "*disabled by society, not our bodies"* (Shakespeare, 2013, p. 20), which took hold of and powered activism.

Sometimes also referred to as the British or Strong Social Model of Disability, it emerged alongside the North American approach to minority groups and the Nordic model, with the aim to bring a focus on understanding the environmental and societal factors which create the barriers that 'disable' people with 'impairments' (Shakespeare, 2004). For instance, steps would be seen as a barrier to a wheelchair user entering a building, not because they use a wheelchair and cannot walk into the building. Inflexible working hours or policies, a lack of support or technology, or an inaccessible office might prevent someone who is neurodivergent or who lives with mental health problems from fulfilling a job or research contract, for instance.

At the time of its publication, in the mid-1980s, seminal studies to 'prove' the social model began to appear, such as Groce's contribution of *'everybody here spoke sign language'* about the adoption of deaf culture in Martha's Vineyard (Groce, 2019). Groce demonstrated through her work with a community on the island, many of whom experienced hereditary deafness, that when everybody spoke sign language, the barrier – 'disability' in effect – was removed. The impairment was unproblematic when society removed its barrier (not speaking sign; ibid.).

The social model's view would understand environmental, social and political factors which prevent the participation of disabled people as a key source of collective struggle, a collective campaign concern. This approach would reject any notion of measuring the disability based on a register of an individual's functioning or bodily ability as the main source of struggle. This societal emphasis offers an opportunity for collective organisation and a focus on structural and transformational change, not individual impairment issues. Campaigns for disability justice in the Global North have tended to place attention on these aspects, such as legal rights, inclusive design of the built environment, and access to work, and the CRPD reflects this approach too. Slorach summarised the impact of the social model well, in an obituary of Oliver in 2019, he said:

> *"his single biggest achievement (was)… to develop an understanding of disability which equipped a generation of activists with a vital tool to fight against discrimination and for genuine social change — an understanding which will continue to inspire their successors"* (Slorach, 2019, n.p.).

Slorach's interpretation of Oliver's work also sought to highlight its relevance to an anti-capitalist agenda (ibid.) and it is worth exploring this a little further now.

2.2.5 Marxism and disability and the materialist dialectic

In the UK the social model found its roots in the materialist tradition (Shakespeare, 2013). The social model's collective approach also shifted the focus of disability research and analysis away from the individual with a medical 'problem' towards the notion of the social construction of disability as a term.

Some more recent disability scholars have gone as far as to suggest that the individualist dialectic on disability is, at its very heart, a concept inherent to "*the exploitation present within capitalism"* (Mladenov, 2020, p. 52). Some have argued that even recognising the disabled/non-disabled binary has been tied to the consolidation of industrial capitalism (McRuer, 2010), through its role in pitting one part of the oppressed class against another, negating the obvious need to consider the more structural factors that keep all working people subjagated.

Marx's presentation (Marx and Engels, 1948) of this *alienation* of one section of the class of working people from another, based on rudimentary externalities and discriminatory factors, has been further developed by Fraser (Fraser, 2014). Fraser (2014) suggested that behind the Marx's 'hidden abode' lies exploitation of people through alienation of differing groups from each other. Particularly, stable neo-liberalism requires the exploitation of women (though the 'free' reproduction of labour to re-fuel the working class), the environment (through its destruction at apparently no capitalist cost), and the use of the state to prop up the capitalist economy to the benefit of capitalism itself (which could not survive without this regulatory support (ibid.).

It is interesting to reflect on this in terms of the concepts of justice which will follow, because the understanding of disability one seeks to overlay then determines the routes to justice available. Thus, it is a topic to which we shall return.

Neo-liberal capitalism as the backdrop to everything

Another vital aspect of the disability debate this raises is the notion of productivism (Mladenov, 2015b, 2017a). Mladenov defined 'productivism' as the modern focus on value as derived through economic contribution - and 'otherness' as a mechanism for exploitation (in this case due to disability identity; (Mladenov, 2017a). More recently, Mladenov went on to expand further this idea. Borrowing the term 'performativity' from Jean-François Lyotard's 1994 essay on post-modernity, he made the case that "the principle of performance enhancement [is] governing the world of contemporary techno capitalism" (Mladenov, 2020, p.51). Mladenov was particularly concerned with the adoption of increasingly neo-liberal framing, and administrative shrinking of the disability category as it become marketized (ibid.). He argued:

> *"In a world governed by this principle, humans and non-human entities exist and are recognisable as good and true to the extent to which they are useful. Performativity is the ontological, ethical and epistemological principle of postmodern capitalism, where torn safety nets and rising indebtedness coalesce with new and emerging technologies to subject people to ever increasing pressures for performance enhancement"* (Mladenov, 2020, p.52).

This may be the case if these aspects are viewed as a function of the economic system itself. As the empirical chapters will outline this comes to be a core aspect of the investigation. But it is helpful to consider here, what we mean by the economic system.

Debates about 'the deserving poor' have dominated the Global North welfare's discourse and public policy, yet, even as early as the mid-1980s, Deborah Stone argued:

> *"the concept of disability is fundamentally the result of political conflict about distributive criteria and the appropriate recipients of social aid." (Stone, 1984).*

Hence authors have highlighted the intertwined nature of modern capitalist pursuit of neo-liberal policies with disability (Mladenov, 2020; Slorach, 2015; Soldatic and Grech, 2016) and have sought to offer meanings to this complexity. For instance:

> *"In the second part of the 20th century in the countries of the Global North, cash-based disability support underwent a gradual shift from compensation to extra-cost support, from conditionality to unconditional provision, and from targeting (means-testing) to universality…The global rise of Neo-liberalism since the 1980s (Harvey, 2005) has slowed down and reversed the trends [and constricted who counts as disabled.]"* (Mladenov, 2020, p. 55).

It is helpful to define neo-liberalism at this point, and I also borrow Harvey's definition highlighted above (emphasis my own).

> *"Neoliberalism is in the first instance a* ***theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms*** *and skills within an institutional framework characterized by strong private property rights, free markets, and free trade. The role of the state is to create and preserve an institutional framework appropriate to such practices. The state has to guarantee, for example, the quality and integrity of money. It must also set up those military, defence, police, and legal structures and functions required to secure private property rights and to guarantee, by force if need be, the proper functioning of markets. Furthermore,* ***if markets do not exist (in areas such as land, water, education, health care, social security, or environmental pollution) then they must be created, by state action if necessary****. But beyond these tasks the state should not venture. State interventions in markets (once created) must be kept to a bare minimum because, according to the theory, the state cannot possibly possess enough information to second-guess market signals (prices) and because powerful interest groups will inevitably distort and bias state interventions (particularly in democracies) for their own benefit"* (Harvey, 2005, p. 2).

The two areas I have highlighted are significant to this debate because they immediately indicate where the disability discourse is headed following this theoretical perspective; this is toward market access to everything from AT to care, and on an individual basis to aid contribution towards the productive output of society. This approach is relevant to the debates about AT access we shall come on to discuss. Mosse, references Harriss-White, too, to consider what this can offer our understanding of disability as a concept:

> *"Disability is not primarily an individual physical condition, but the 'socially-defined incapacity to work' (Harriss-White, 2005, p. 882). The condition of disabled people is the result of 'tactics deployed by others to force unemployment' (Harriss-White, 2005)" (Mosse, 2010, p. 1158).*

I shall discuss this further throughout as no matter the viewpoint one takes on the positive or negative influence of neo-liberalism, one thing is clear: this investigation cannot negate its present political, economic, and social context. Now, I return to the critique of this strong social model approach.

2.2.6 Challenges to the Strong Social Model from the Bio-Psycho-Social Model

However necessary, the social model was a tool to refute the medical model, contributor to the Global Report on Disability (2011), Professor Tom Shakespeare, suggests that the Strong Social Model lacks hard evidence and intellectual strength (Shakespeare, 2013, 2007, 2004). In early work with Watson, he suggested:

> *"It [the social model of disability] could be reduced to a slogan: 'disabled by society not by our bodies'. Organisations and policies could be easily evaluated: did they use the (social model) term 'disabled people' or did they use the (medical model) term 'people with disabilities'? Did they focus on barrier removal, or did they focus on medical intervention and rehabilitation? The social model could be used to view the world in black and white, even if this was not the intention of those who originally framed it. Psychologically, people's commitment to the social model was based on the way it had transformed their self-esteem. Any individual who had become an activist on the basis of joining a collective united by the social model ideology had a*

> *deep investment in the social model definition of disability. 'We' were oppressed: 'they' were oppressors. 'We' talk about disability, we don't mention impairment. You can't be a proper activist, unless you accept the social model as your creed"* (Shakespeare and Watson, 2001, p. 11).

Later, he developed his thinking further suggesting that:

> *"the British materialist transition in disability studies that has successfully inspired generations of activists has not translated into an adequate body of good empirical research, perhaps partly because of the reliance on overtly narrow and reductionist conception of disability"* (Shakespeare, 2013, p. 1)

In the first edition of seminal work Disability Rights and Wrongs (2007) Shakespeare acknowledged that much had been won through a social model approach, though concluded that disability politics and disability research needed to move beyond *'the social constructionist impasse'*. In his 2014 'revisited' version, he argued that the Strong Social Model of Disability does not represent a sufficiently robust theoretical perspective to guide research nor enhance the everyday lives of disabled people around the world (Shakespeare, 2013, p. 2); disputing the conflation of political call to action with social theory, he argued it tends to be over-focused on structuralist (Marxist) interpretations or overcommitted to theoretical, cultural propositions. The cost, he argued, of this Strong Social Model dominance was offering "*not much in the way of practical help in understanding the lives of disabled people, never mind changing them for the better"* (Shakespeare, 2013, p. 3). His rejection of the 'strong social model' is based on three key factors:

1) Firstly, to ignore the very real role of impairments in the lives of disabled people is to dismiss the need for rehabilitation [and, as this research suggests, AT], and to deny the real impetus to act which reduces the incidence and impact of impairments. The "*social and biological are always intertwined"* he was clear to explain (Ibid., p22), giving the example of pain, which is often a feature of disabled people's lives. Pain has multiple sites of dynamic causality, including psychological response, lack of access to drugs, lack of AT or inclusive environments, and a similar multiplicity of solutions for relief which interact between the social and biological. This has relevance in the case of low-resource settings where access to drugs and AT is often limited by financial, not biological or medical, concerns and therefore has particular relevance to this study.
2) Secondly, the rejection (by social model advocates) of the need for any framework within which to measure impairment or disability is problematic, Shakespeare argued that it negates the need to have much more, rather than less, robust evidenced-based theory and policymaking. In global health terms, decisions about resource allocation and investment into issues such as AT, or preventable diseases which cause impairments, are shaped by a return-on-investment framework which cannot be influenced (to support more disabled people) without better evidence. Hence if one accepts Shakespeare's first point, the second follows almost by necessity.

Thirdly, he argued that the Strong Social Model results from identity politics, not a genuine theory of social change. Hence, contrary to its rhetoric, the Strong Social Model runs the risk of incorporating disability as an essentialist identity, based on a set of characteristics, at the expense of setting the struggles of disabled people within a systemic understanding of the complexity of diversity and a strategic response based on the transformational, collective levers for social change. This last point is particularly relevant to this study. As we shall discuss, (Fraser, 2008, 2005, 2000) similarly warned of the implications of such reification of falsely understood and extracted identities.

All of this becomes significant to understanding the context for this work because if one adopts a definition of disability which does not itself connect to a genuine theory of social change, it is difficult to place this within a trajectory of justice. Hence Shakespeare offered just this. Shakespeare made a strong case for an evolution of the Social Model of Disability, which recognises more than just the socially constructed elements: the Bio-Psycho-Social (BPS) model. The BPS model accepts the social argument as well as factors in the realities of biological (impairment-based) and psychological (personal response) characteristics too.

The fundamental problem addressed by Shakespeare is the fact that the social model takes for granted whether, in fact social phenomena are ontologically ‘real’ and more so than physical and biological conditions (Kristiansen and Kermit, 2007) instead viewing disability as a complex interaction between intrinsic and extrinsic factors (Shakespeare, 2013), borrowing Hacking’s (1986) deconstruction of social construction.

Suffice it to say, I find the BSP model convincing, to the extent that it may well take a better account of the everyday experiences of disabled people in low-resource settings where (lack of) access to pain drugs or assistive technology does make an enormous daily difference, and where cultural understandings of disability affect stigma and psychology in authentic ways. However, for this study, I will focus primarily on the **social** element of individual impairment while scoping out its medical and clinical elements, while , focusing on disability as a collective social identity.

Another element of disability studies which is vital to understanding, especially the context in the Global South and DJ, is the radical ‘Crip Theory’ movement.

2.2.7 A side note on stigma

Throughout this thesis the reader will see repeated reference to stigma. This could be the subject of an entire thesis itself. However, it is necessary to adopt a definition of stigma, due to the repeated nature of its presence in the data. In the first published paper from this work (Austin et al., 2021a) stigma is understood as comprising complex interaction between culture, perceptions of value, and the nature of disability identity. A nuance was added around the intersectional aspects of gender and informality in the paper.

This definition is adopted for this thesis. What is also important to note is the particular lens of internalised oppression, which arises further in the data from the participants and international experts. David and Derthick (2013, p. 23) have described internalised oppression as: “uncritical devaluation of own’s own group and valuation of another…which is commonly experienced by members of oppressed groups”. in this case disabled people devaluing themselves and others that have a disability identity is the application. As shall be explored in the empirical chapters, this occurs in the data – often it is described as an ‘expectation of exclusion’ by participants.

2.2.8 Critical Disability Studies & Crip Theory – the embodiment of the disabled body

‘Crip Theory’ is one strand of critical theory that has been used to resist the normalising assumptions of able-bodied heteronormativity (McRuer, 2006). Building on queer theory and feminist theory Crip Theory offers a relevant critique of the ‘mainstream’ Social Model of Disability as too simplistic due to its negation of the importance of intersectionality - especially queer and feminist perspectives. Crip Theory draws much upon personalised narratives of disability as a starting point for investigation. For instance, Goodley and Runswick-Cole (2013) aimed to explore how the impaired body can be embraced as a unique embodied entity which offers, in turn individual solace and strategic challenge to what we imagine normalisation of the embodied experience to be. Referring to Shakespeare and Watson’s (2001) description of the disabled body as an ‘absent presence’ in critical disability studies, prominent work refers to theories of ‘affect’ to build out to theoretical constructions (Goodley et al., 2018). The nature of the embodied experience goes to the need to recognise and value the individual’s identity as valid and subjective:

> *“Instead of framing disability as a problem of individual bodies, where the solution to difference is found in often deeply harmful rehabilitation, and intervention, disability studies and Crip theory allow for a more critical and expansive look at disability as an aspect of identity and culture that holds inherent value”* (Hanebutt and Mueller, 2021, p. 1).

As Snyder and Mitchell (Snyder and Mitchell, 2010a) suggested, perhaps a value of transgressive re-appropriation (such as Queer or Crip Theory) can motivate resistance, political commitment and disruption.

As early as 2006, consideration of the role of technology in enabling or disabling interactions, was discussed in the literature (Moser, 2006), building on the idea that disabled is not something a person ‘is’ but something a person ‘becomes’ or is ‘made’ through the interactions they experience (Moser, 2005).

> *In many countries the idea of normal bodies, and normalisation of difference is commonly accepted, and this locates agency and mobility in a ‘normal’ human body… “measured against this norm, disabled people will always be constituted as Other, as deficient and dependent…they will never quality as competent and able persons”* (Moser, 2000, p. 201).

Critical disability studies theories also question the Social Model in terms of its rejection of practical realities for living in ‘the majority world’ (the term used to describe the Global South), often in conditions of poverty. Goodley (2014, p.201) built out his *‘critical ableist approach’* defining critical disability studies as “*starting with disability but never ending with it, viewing disability as a space from which to think through a host of political theoretical and practical issues relevant to all”* (Goodley et al., 2012).

Their critique of the (in their terms) ‘mainstream’ Social Model is that it is too simplistic and lacks a thorough interrogation from the Global South perspective. These authors found the locus of traditional disability studies with its Global North anchor lacking, and potentially even reproducing neo-imperialism.

I suggest that this perspective is useful in reference terms and can inform the need for this work to relate to the specific and lived experiences of poor disabled people' in the Global South, relevant personal stories. However, critical disabilities studies have a tendency to pose, rather than answer questions – important though that is, it does not provide 'enough' to answer the research questions here. Nonetheless, the 'critique' informs our investigation, especially as it is centred in the Global South development terms.

2.2.9 A Capability Approach theory of Disability

Looking more broadly to development, the Capability Approach (CA; (Nussbaum, 2003; Sen, 1999) offers a model of development as facilitating human freedom by enabling people to pursue '*the things they value'*, themselves. This focus on *agency* and participation is central to this study because it foregrounds poor disabled people as active agents of their own liberation (Nussbaum, 2003).

Significant attempts have been made to map the CA to disability with varying degrees of success (Bickenbach, 2014; Mitra, 2006; Trani et al., 2011). Since it is a very theoretical position – albeit with very simple practical extrapolation, in principle if not in practice - the CA's human wellbeing vision is in line with disability inclusion or justice. Human freedom, perceived as a very core point or rationale of development, is measured in the CA according to the *capabilities* (what people have capacity to choose) a person has and their individual *functioning* (day to day things people can do or be) which are (re)constructed in differing formations to make up their capability set (Frediani, 2010). In this way "*development can be seen … as a process of expanding the real freedoms that people enjoy…Focussing on human freedoms contrasts with narrower views of development, such a identifying development with the growth of gross national product, or with the rise in personal incomes, or with industrialisation, or with technological advance or with social modernisation."* (Sen, 1999, p. 1,3).

Mitra has suggested that disability could be viewed either as a deprivation of capabilities, or functioning - the former potentially more nuanced, but the latter easier to observe (Mitra, 2006). However, the CA has rarely been used operationally in meaningful ways because of the resulting complexity of applying the theory in practice to varying impairments in varying contexts. Most recently Pineda (Pineda, 2020) a prominent academic and disability activist, offered a new take on this theoretical positioning with a Capability Theory of Disability which draws out the importance of CA as a set of principles to inform our understanding of distributive justice as fundamentally participatory, and deliberative, "*where social values are developed and implemented by the most affected"* (ibid., p.25) but this has yet to be extensively tested.

The principal focus the CA offers on the 'agency aspect' (Alkire and Deneulin, 2009) can be combined with the underlying hypothesis of autonomy held up by the disability movement's claims to the SMD, to make the strong case for participation as a 'means as well as the ends of development' (Sen, 1999) . For this study, we take this forward as a guiding principle. However, when the CA has been 'operationalised' as the attempt within the WHO's International Classification of Functioning (ICF) – the results have not always felt aligned with such a principled approach as shall now be shown.

2.2.10 A side note on language

Language and the culture it espouses can give a clear indication of social norms and practices around disability. Language like 'handicapped' or 'wheelchair-bound' give the clear impression of a medical approach which pours focus and pity on the disabled person. Some have suggested that the shifting nature of disability language represents both administrative categorisation (relating to who can access public support) and a market based construct (Mladenov, 2020), creating demand for bodily and mental 'improvements' (for instance through eugenics) to enable greater productivity (Snyder and Mitchell, 2010b).

Language itself can be viewed as part of the social infrastructure which disables individuals with impairments, thus, in disability policy and parlance terms, language remains a significant debate. For instance, '*impairment'* is used within the social model to describe a medical condition, rather than naming 'a disability' which confers the ownership for 'lack of ability' to undertake a certain activity on the individual, rather than society. From this perspective impairments merely represent a difference, or diversity, in the human condition. It is quite common for deaf people's organisations, for instance, to suggest deafness is simply a linguistic minority rather than a medical condition or disability and hence: D-eaf community (the proper noun, name or a group) rather than d-eaf community (an adjective).

In the UK, followers of the social model, including most DPOs, refer to '*disabled people'* rather than 'people with disabilities' because this term respects the fact that 'people' are 'disabled' by society, rather than their bodies. 'Disabled people' is reclaimed language and intentionally so. When interpreted in context, this nuance does not always translate. In SL, for instance, the term *disable people* (sic) is often adopted in common parlance (possibly following NGO intervention), but arguably without the same 'reclamation' since stigma and discrimination are very apparent and direct.

In most of the rest of the US-dominated Global North, the term *people with disabilities* is adopted, with the suggestion that 'people first' language is appropriate rather than a definition of a person as 'disabled'. The UN uses the rather legalistic and impersonal term *persons with disabilities* which tends to get shortened to the US approach, and the implementation of the Human Rights work of CRPD has tended to find its way into the legislative frameworks of the Global South nations engaging with disability for the first time in focus through the CRPD. Yet, *people* or *persons with disabilities* is not strictly recognising disability as a factor constructed by conditions other than the body of the impaired person in its construction.

This debate could be the topic of an entire thesis. Suffice to say, this work adopts the term *disabled people* throughout, for it aligns most closely with the model of disability which recognises the constructed and social nature of the experience of disability. There are some notable exceptions to the adoption of the term *disabled people* which are found in the direct responses of participants' use of language which differs, or when engaging with UN-related organisations. Now we turn to the construction of the UN Human Rights-based approach.

2.2.11 Attempts to operationalise Models in practice – ICF and the Washington Group

Following the Human Development (capability) approach in name, the WHO developed the International Classification of Functioning (or disability) or IFC. The IFC was intended to respond to the need for more disability data on which to base policy, and – to be fair - this has led to many examples of collecting such data (WHO, 2001). It is very difficult to argue, though, that the principle of the CA is carried through into practice of the IFC, and a look at the implementing framework shows a heavy reliance on commensurate measurable (medical) impairment data at the expense of better wellbeing information.

Further, on data collection, the Washington Group for Statistics (based at UCL) have also formulated six 'Short Set Questions', which can be included within national data collection tools. However, these indicators are naturally proxy, contested, require very careful contextual translation, and therefore can be expensive to use and should be complemented by person-centred narrative. Additionally, for a population that has previously been largely ignored, quantitative evidence of impact is a valid 'tool in the box', designed to enable countries to base decisions on evidence. However helpful it is to avoid invisibility, poor classification can stigmatise and discriminate too. Avoiding the misrecognition and reification of disabled people becomes a central question.

2.2.11.1 Connecting a relational understanding of disability to a relational understanding of poverty

Coming toward the conclusion of this review, then, while the radical ideas and advanced thinking birthed the social model, and the greater focus on individual preferences of the CA, a relational aspect to disability has not yet been explored. That is to say the social relations which give rise to disablement were somewhat overlooked in 'the heat of the debate about this model itself' (Thomas, 2004). This raises the question so clearly articulated by Woods in the case of urban poverty; if poor people are poor 'because of others' (Woods, 2003) are disabled people disabled 'because of others'? Does the construction of a society which is ableist in its social relations, and discrimination in the practice of its social relations, have an important role to play in our understanding of disability in context? From the perspective of this research this is a relevant avenue to explore.

Human geography scholars have sought to address this question with a specific reference to the built environment, following the separation of understanding between functional ability (of individuals) and social experience or ability to participate (related to environmental barriers). Gleeson, first explored the notion of social environment, not a pre-determined and oppressive, but rather as contexts which interact with and are co-produced by the person enacting with them (Gleeson, 1999), which also offers some evidence to this point.

Additionally, a body of work on Disability and Non-Representational Theory (Hall and Wilton, 2017) exists building on Thrift's (2008) thinking. Instead of considering relations alone, this work also looks at the embodied experience of practices and performance between humans and non-humans (not simply their outcomes; ibid.). Though this begins to be out of scope for this research, it does raise an important point when considering the limitation of embracing and extending the links between Non-Representational Theory and disability. It helps to recognise that:

> *"all persons (both disabled and non-disabled) depend to a greater or lesser extent on human and non-human others for their capacity to act"* (Hall and Wilton, 2017, p. 739).

This point will be important when we return to the use of assistive and other technologies. Interbeing, or reliance on relational context, raises the need to both understand the diversity of experiences disabled 'others' face, and to foreground the relational dependencies which specifically allow those with 'able bodies' to act with ease, while others cannot (Hall and Wilton, 2017, p. 740).

2.2.12 Conclusion: participation and identity

Identity can be understood in many ways. Beneficial is a summary as a delineator of *'who's who and what's what'* (Jenkins, 2008). Although certainly, a balance between avoiding reification (meaning making it more concrete than it is) of disability identity (Fraser, 2000, 2010) and overcoming invisibility, so that disabled people can make their demands, is required. Thus identity, belonging, stigma and acceptance are seen as interconnected terms, with shame being one of the most primitive and universal human emotions, which, when hidden, can damage resilience (Brown, 2006); as Grue suggested:

> *"The strategic problem for the disability movement has to do, at least in part, with getting people to identify themselves and others as disabled – specifically, with getting people that would not ordinarily accept an identification as disabled to 'come out' as such. This metaphor – borrowed from the LGBTQ movement – suggests that disability is an authentic identity obscured by an inauthentic, but more socially acceptable identity. But if disability is a higher-level, more abstract identity than identities oriented towards specific illnesses or impairments, and the disability community can only be conceived in fairly abstract terms, this project may prove more challenging than has previously been assumed"* (Grue, 2016, p. 962).

Citizen activism has often been the route that disenfranchised people took to generate change. However, when one is not only fighting maldistribution (of wealth) but also misrecognition of multiple and intersecting identities, and a lack of political representation (ibid.) this can become impossible. Some wonderful examples do exist - see for instance *The Fight*, a documentary about a group of wheelchair users who led a caravan from Cochabamba to La Paz for their claims in Bolivia - but often the day-by-day struggles of poor people often fail to take account of the experiences of poor disabled women and men.

The 'invisibility' of disability in the literature on urban poverty, is a case in point, which will discuss more later in this chapter. This absence means that the voices of poor disabled people, especially women, are infrequently heard and their experiences are rarely conceptualised. Rarely do the struggles against urban poverty and those for disability rights intersect, and ultimately this is to the detriment of those who need to benefit from claims-making around poverty and disability, not those with the power to withhold change.

There are many approaches to disability outlined above. This study does not seek to offer resolution to these complexities – in fact there is much to challenge this 'ordering discourse' which assumes there is some strategic overlaying 'truth' through which ideas can come together in one singular narrative which also works to order disability in society (Moser, 2005). Life is complex and subjective, so too is the embodied experience of disability.

As this initial discussion has shown, disability can also never be divorced from the cultural context, as Baylis explains:

> *"What is recognized as impairment or as disability varies across cultural contexts, but societies are also implicated in fundamental ways in the creation, maintenance and*

> *intensification of impairments and their translation into disablement"* (Baylis, 2002, p.726).

Following the discussion above, I rely primarily on the social model view of disability, nuancing this thinking regarding the relational, contextual distinctions. I will focus on the agency and participation of those who experience disability identity, as central to any notion of justice or emancipation, not just in terms of achieving as set of claims or outcomes which are better than before, but also because of the empowerment that participatory claims-making can offer. I move on now to discuss AT, with this understanding of disability shaping focus.

Summary of Key themes identified in this section with relevance to the framework

- A relatively strong global policy framework but a lack of country specificity and paucity of data
- A rejection of medical models of disability and a broad **adoption of the social model approach** (Oliver, 2013) which acknowledges the realities the BSP model makes explicit, but remains focused– for this study – on the social construction of disability as an identity.
- An understanding of the ways in which the **neo-liberal social, economic and political system** (Harvey, 2005) provides the conditions within which disability interventions are decided upon and observed.
- Aligned, there is a renewed focus on **productivity** (Mladenov, 2020, 2015a) as a desirable function of human input, rather than human flourishing of joy.
- The idea of **disability as a relative and interdependent concept** (Hall and Wilton, 2017).

2.3 Disability and Assistive Technology

2.3.1 Introduction

In the following sections I will set out first, the discussion about the definitions of AT considering the heritage of the term in the literature as well as the currently adopted global definition. Secondly, I explore AT in Global Policy - the current actors and their frameworks for intervention. Thirdly I will consider recent evidence in the AT sector, organised against the themes of the recently published Global AT strategy by AT scale. I will draw on both published material and grey literature in this section. Finally, I will consider a more critical analysis – the commoditisation of aid and expectations of 'usefulness' that some assign to AT use and access. This sub-section will finish like the others with conclusions and the salient themes for the framework summarised.

2.3.2 Defining AT

WHO estimates that there are currently more than a billion people who need access to AT - like hearing aids, eye glasses, wheelchairs, walking sticks and the services that wrap around those products to make them usable, safe and life-enhancing (WHO, 2016). AT makes the impossible possible for many people, most of whom are disabled or older people (ATscale, 2020). At present it is estimated that 90% of those in need of AT do not have access to it, some 900m people, and the number in need is set to double by 2050 with no alleviation in the access gap unless something significant changes (ibid.). It is for this reason that donors, multilateral agencies, and even some market players have begun to awaken to the pressing need which individuals, NGOs and governments have been aware of for some time (Austin and Holloway, 2019).

WHO has a definition of AT which is set out below.

Assistive technology is the application of organized knowledge and skills related to assistive products, including systems and services. Assistive technology is a subset of health technology.

Assistive products: Any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual's functioning and independence, and thereby promote their well-being. Assistive products are also used to prevent impairments and secondary health conditions.

Priority assistive products: Those products that are highly needed, an absolute necessity to maintain or improve an individual's functioning and which need to be available at a price the community/state can afford.

Source: WHO Priority Assistive Products List

This definition of AT refers broadly to the Assistive Products (AP) and the AT systems, within which they are provided, for instance screening, referral, prescription and AT training facilities. This **priority-products-plus-services** approach was established as the relevant definition in a 2015 Lancet paper (Khasnabis et al., 2015) which coincided with the International Day of Persons with Disabilities (IDPD) and highlighted that *"assistive* *technologies are crucial mediators for realising people's rights, and for promoting access and empowerment"* (ibid.) which was the theme of IDPD that year. We shall interrogate this lineage further below.

AT is not universally lacking. In fact, in some richer countries the availability of AT is such that the rate of abandonment of assistive products (AP) is actually incredibly high (Holloway and Dawes, 2016). However, the majority of disabled people in the world – 80% - live in low resource settings in the Global South (World Health Organization and World Bank, 2011), and these people are most in need. A 2018 scoping report on access to AT found that: *"the lack of AT for the poorest compounds intransigent poverty in complex and multi-faceted ways…yet this is rarely recorded or quantified, never mind tackled"* (Holloway et al., 2018).

2.3.2.1 Defining AT historically from the literature

Definitions are critical for assistive technology (AT) yet inconsistent, sometimes contradictory, and often a broad loose definition has been adopted to enable a more inclusive approach (Abbott, 2007, p.6). Layton et al. (Layton et al., 2020b) provide a wonderful overview of the history of AT since 2000 (shown in Figure 3 below), which begins with the International Collaborative Agreements of AT Associations, which becomes GAATO in 2019. They highlight only the CRPD (2006) and the WRD (2011) before the 68th General Assembly of the UN request WHO to set up GATE – the WHO AT team – to orchestrate global collaboration, in 2013.

Historically, AT has been defined in many ways. One can trace back the history of specialist devices for disabled people to a very medical origin, much less linked to independence and empowerment of the user. Prior to WHO, the Foundation for AT adopted the following definition in 2001:

> *"any product or service designed to enable independence by disabled or older people"* (Abbott, 2007, p. 6).

One can see the evolution of thinking toward the WHO adopted approach. As Abbott et al. commented though, consistency has evaded the field, largely as whilst AT has a commendable history of good intentions it suffers from a less-than-consistent understanding of its meaning (Abbott, 2007). This general framework is still useful, and the current WHO definition expands on it with more precise language for the World Health Assembly Directive, which defines it as:

> *"a subset of health technology, refers to assistive products and related systems and services developed for people to maintain or improve functioning and thereby promote well-being." (World Health Organization, 2018, p. 14)*

Figure 3: Assistive Technology Milestones since 2000 (taken from Layton et al., 2020)

According to the WHO resolution, highlighted in Figure 3 above, AT makes it possible for those who struggle with their ability to function to have active, healthy, independent, and respectable lives, taking part in social, economic, and educational activities (World Health Organization, 2018).

The word 'function' is used explicitly in this description to refer to what people will be able to perform because of having AT. The WHO definition, as set out here in the World Health Assembly Resolution, refers directly to the use of structured knowledge and skills in relation to the provision of assistive products, including systems and services necessary to provide those products, in the form of AT. The device, or assistive product, is a critical element of AT, but it should be taken together with the services necessary to deliver it safely.

The International Standards Organisation (ISO) also provides a definition centred on the product and its use to improve wellness, too:

> *"An assistive product is any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual's functioning and independence, and thereby promote their well-being. Assistive products are also used to prevent impairments and secondary health conditions"* (Internatio nal Organization for Standardization, 2022, p. 3).

The information above shows a historically broad and unaligned definition of AT, followed by a clear and present definition by WHO, which is adopted by all countries who view the World Health Assembly and will form the basis of the Global Report on AT to be published in 2022. Therefore, I adopt the WHO definition of **priority products plus services** for this investigation. However, as we shall see below and in the empirical chapters, it is not perfect given the proliferation of technology and the realities for poor, disabled people.

2.3.2.2 Accessible, 'ubiquitous' mainstream tech – the proliferation of what is assistive?

Accessible technology is different from AT because it is mainstream and designed for everyone to use. It has a rich history in the field of human-computer interaction (HCI) (Holloway and Barbareschi, 2022). Holloway and Barbareschi's recent Disability Interactions (DIX) manifesto gives a history of HCI and the broader move to address accessible technology, starting with alternative and augmented communication aids (AACs) which were developed in 1969. It was one to two more decades, though, that accessibility became more mainstream with the primer HCI conference in 1986, entitled: *Human interface design and the handicapped user* (Buxton et al cited in Holloway and Barbareschi, p71*)* which lit the touchpaper for more research although the work remained niche due to the lack of market interest (Glinert and York, 1992 again cited in Holloway and Barbareschi) – it was in fact the Americans with Disabilities Act (ADA) in 1990 that sparked the legal requirements necessary to ensure accessible content and devices (ibid).

The ADA also sparked a movement for Universal Design of both physical and digital spaces. Holloway and Barbareschi (ibid.) revealed that it was this universal design movement which led to two important shifts in the design of technology: the need to consider a wide variety of user needs from the start of the design process (Persson et al., 2015), and mainstreaming of accessibility (Stephanidis et al., 1998) leading to the Web Content Accessibility Guidelines (WACG), originally established in 1999 by the Web Accessibility Initiative (WAI) of the World Wide Web Consortium (W3C). However, it was not until 2011 that the approach moved beyond focussing on what a disabled person cannot do, and moved into the field of creating more adaptable technologies for all. This was proposed as *ability-based design* by Wobbrock et al, (Wobbrock, 2017, cited in Hollowy and Barbareschi, 2022). Even with this shift there is still a focus on functional ability and on developing interactions which will help with employment and learning rather than a full spectrum of life, like taking part in activism, fun or activities that promote jobs – activities that (Piepzna-Samarasinha, 2018) recognised as vital to DJ.

A clear critique of the accessibility of increasingly ubiquitous technology, such as smartphones, is that it is not truly global and, ignores much of the low resource reality in the Global South (Holloway and Barbareschi, 2021). However, mobile phones have, to some extent, bucked the trend for technology diffusion; unlike infrastructurally heavy technologies, like computers, which have a penetration rate of 25% in LMICs (James, 2013), the mobile diffusion rate is much higher, for example, it is estimated to be 91% in Nigeria (Jumia, 2019) cited in (Holloway and Barbareschi, 2021)

Increasingly, WHO and others are promoting mobile phones as AT, and this is an aspect of this study that deserves further investigation. The AT2030 programme, with the GSMA (the mobile phone providers network organisation) conducted a study published in 2019, to consider the mobile access gap for disabled people to supplement the work done on mobile as an empowering tool. The report (GSMA, 2019) followed a robust research methodology using data from a GSMA consumer survey in seven countries. It found that disabled people have lower levels of mobile phone use than non-disabled people in all countries (Algeria, Guatemala, India, Kenya, Nigeria and Pakistan), and in Bangladesh, there was the widest gap of 55% less likely ownership of mobile phones. Kenya and Pakistan had the least gap (of 11%). Despite the potential of smart phones to act as AT, disabled people were also less likely to own smart phones, rather feature or basic phones were more common, that have less accessible functionality. There was also a significant gap in mobile internet uses of connectivity which was found to be a specific barrier with fewer disabled people aware of the value of mobile internet in terms of accessing applications that might help. Finally, literacy and digital skills were also major barriers (GSMA, 2019).

It is helpful to be critical too though, and for sure it must be stated that the GSMA are overtly set up to drive business to their operators – mobile phone companies. Their interests are interlinked with that of extending purchase, use and internet access for smart phones. Nevertheless, Holloway and Barbareschi (2021) also concurred with the value of mobile; one relevant example of this is an ethnographic study conducted with disabled people from Sierra Leone, which showed how people leveraged AT and ICT to promote an image of themselves as competent and technically savvy to contrast the stereotypical label of people with disabilities being seen as helpless by other members of the community (Jones and Pal, 2015). They found: *'that technology was a crucial tool for combating social dampeners in everyday life and for supporting a primary goal of the UNCRPD: enabling full participation in society for people who have sight and mobility impairments.'* (ibid., p.10)

Moving from mobile as assistive technology now, to mobile as assistive in support of social movements, the next section addresses this point.

2.3.2.3 Smart Cities and Emancipatory Communication Technology

Another way in which this study interacts with technology, is through technology which can potentially be used for campaigning for justice. Much is made of the power of social movements enabled by digital networks. Yet, Milan highlighted that although in theory there is much to like in new technological developments around the use of smart technology for activism, “for instance, the ability of digitally mediated political engagement to speak to broader and diverse audiences” (Milan, 2013, p. xiii), the risks are equally present, associated with the dominant ownership of platforms by market actors, state monitoring, corporate filtering processes, surveillance and content restriction. She suggests that “the ‘social’ of social media has not done much for emancipatory politics” (ibid., p.17).

For most of the people who now live in cities[3], their everyday lives are affected by the smart technology which is increasingly being embedded into the fabric of the public spaces. Referred to previously as ‘wired’ (Castells, 2009; Dutton et al., 1987) ‘telecommunications’ (Graham and Marvin, 1995), ‘digital’ (Ishida, 2002), ‘intelligent’ (Komninos, 2009), and creative (Florida, 2002) cities – among other things – the notion of harnessing technology for urban development is of some considerable age. One thing is common though, the new smart cities, or new elements of smart-ness within existing cities, tend to be led by technologists (Townsend, 2014); that is companies with their interests tied to the success of this new model of city building, built in tempting partnerships with city authorities. PlanIT, near Faro (built by Siemens) and Sondo City, South Korea (IBM) are just two examples. The ‘Smart City’ paradigm can be understood as everything and nothing.

Further, while the tech that makes our cities ‘smart’ is rapidly evolving, driven by civic hackers and social entrepreneurs, corporates and public administrations for entirely different (though sometimes similar) reasons, the use of technology as a means to development is also an old idea, with Harry Truman’s (20th Jan, 1949) famous statement proffering the end of the colonial age based on “a bold new program for making the benefits of scientific advances and the industrial progress available for the improvement and growth of undeveloped areas”.

While the smart technology that dominates in the Global North often takes longer to permeate the Global South, it is possible to see this technology leapfrog the status quo – the widespread adaption of mobile banking in Kenya is a good example (Holloway et al., 2021; Holloway and Barbareschi, 2021). Milan (2013) suggested that “*our existence unfolds in cyberspace as much as it does in real life … (as) a variety of always-on, portable devices, microchips and sensors transform our daily whereabouts to database entries”* (Milan, 2013, p. xiii). Hence this study will give some consideration to the role of smart technology, as a mechanism to social campaigning, and an expression of identity.

Not only are critics of smart cities and the ownership of social media platforms right to raise concerns related to governance and operational agency, but some authors have gone much

---

[3] Today, 55% of the world’s population lives in urban areas, a proportion that is expected to increase to 68% by 2050 (UNDESA, 2019).

further, to suggest that this ‘tech optimism’ is a fundamentally problematic result of the neo-liberal context in which we live. Mladenov (2020) put is succinctly:

> *“Private lives have gotten totally externalised, disaggregated and monitored, with or with- out the consent of their subjects. For one thing, millions have been compelled to share information about their most intimate and mundane activities on social networks on an everyday basis, where their privacies have been quantified and ranked in most superficial terms (‘views’, ‘reads’, ‘likes’, etc.)”* (p.52).

This quote belies the focus that has been given to wantonly sharing data though social means, with notional consent, but the question as to whether this is actually in the interests of the user, or the company that captures and sells on or otherwise capitalises that data, is a core point of contention. For the purposes of this study, while AT accessed through mobile phones (Mobile as AT) is a relevant theme, so too is the political and socio-economic context around provision and access.

For sure then, the technology embedded in the city, and in our everyday lives with the potential to be used for campaigning also deserves attention, in addition to the primary focus on AT, I draw forward into the review the need to think critically about the role of technology in emancipation more generally.

I now move on, and the next section seeks to unpack what we know about traditional AT, using the WHO definition, from a policy and research perspective, and what we do not. In order that I can begin to construct an understanding of the value of AT in achieving DJ in context. I will return to the sceptical technology theme in a broader sense at the end of this section.

2.3.3 AT and Global Policy

The CRPD covers AT in eight separate articles directly, and provision of AT can be assumed as necessary to meet a further 17 articles (Borg et al., 2009). Though *“none of the articles of the CRPD requires actions that cover all basic key areas of assistive technology, such as production, availability, affordability, information, training and use…it may be understood that such activities are included in what is called ‘comprehensive habilitation and rehabilitation services and programmes (article 26)”* (ibid., p.165*)* point out that this is the responsibility of both the national government *and* a matter for international cooperation.

2.3.3.1 Sustainable Development Goals (SDG)

Similarly to the CRPD, the SDGs do enshrine the rights of disabled people and AT is necessary for the realisation of many of the goals as (Tebbutt et al., 2016) set out. Affecting so many people, and with an ageing population, the numbers needing AT to live full lives continues to grow (WHO estimate to 2bn by 2050). Despite this, scrutiny is poor and reporting on SDG performance rarely covers AT (or disability inclusion). While disability data is increasing (for instance through increased use of ‘Washington Group’ questions in measuring disability prevalence in national surveys, AT access has not yet been included in those formal data sets.

Since 2014 (following a UN High Level Meeting in 2013) WHO has led an initiative called GATE (Global Cooperation on Assistive Technology) with a mission to assist Member States to improve access to AT as part of Universal Health Coverage. GATE has become central to the global call of AT provision.

2.3.3.2 WHO GATE Framework for AT

GATE is led by Chapal Khasnabis, an Indian AT expert who built AT himself as a young man in a family business before setting up NGO 'Mobility India'. In the latter part of his career, he has provided somewhat disruptive 'jugard intra-preneurial' leadership - borrowing from the Indian term Jugard Innovation (or low cost innovation) and intra-preneurial, meaning within an organisation. His work within the WHO in Geneva has seen the setting-up of the global agenda of AT (open the) G**AT**E. GATE has built a conceptual model (the 5Ps) which embeds a loose Human Rights Based Approach to Disability, framing as it does against the CRPD and the need to provide AT within inclusive Universal Health Coverage. The central 'P' is for people.

Figure 4: WHO GATE 5P model of assistive technology. People surrounded by Products, Personnel and Provision, which then are surrounded by Policy, Universal Health Coverage, and the Convention on the Rights of Persons with Disabilities

In 2018 GATE received an agreement at the World Health Assembly (World Health Organization, 2018) that set up the World Report on AT and called on members states to *"develop, implement and strengthen policies and programmes to improve access to AT within Universal Health/Social Services coverage…[to meet the aim of ensuring] effective access to high-quality, affordable, assistive products, globally".* I spoke in favour of it at the packed side meeting which had an overwhelming amount of support from nations across the globe. This resolution also called for more research and testing of 'what works'. The Resolution (World Health Organization, 2018) called for a global AT approach which followed that of WHOs essential medicines provision that has reduced cost and improved access to vaccines and medical devices.

Due to the paucity of existing data, work is still ongoing by WHO, UNICEF and partners, to find new sources of primary data on access to AT by which to measure progress and design the first Global Report on AT (GREAT), to be published in 2022. This work has been given focus through bi-annual summits as now set out below.

2.3.3.3 GREAT Summits

The first GREAT (Global Report on AT) summit was held in 2017 and summarised research against the 5P's; People (Desmond et al., 2018), Products (Smith et al., 2018), Policy and systems thinking (MacLachlan and Scherer, 2018), and tools (Layton et al., 2018) were considered regarding capturing and sharing innovation in the AT space. The papers outlined current topic thinking and present recommended actions that are needed to guide and galvanize the collective efforts of all AT stakeholders. Later 'Place' was considered in more depth as the environment was taken more clearly into account:

> *"In many cultures, sitting on the floor, kneeling, squatting, walking barefoot, etc. are essential activities of daily living and community engagement… products need to be developed for users taking into account their functional needs, which may be heavily dependent on the physical and cultural environment they live in"* (WHO, 2017).

This global policy framework has gone on to inform the work on AT which really began to step up with major donor engagement at the beginning of 2018, when UK Aid launched the first Global Disability Summit with AT as a main theme.

2.3.3.4 Global Disability Summit, June 2018

In 2018 the Government of the UK, the Government of Kenya and the International Disability Alliance worked together to host a Global Disability Summit (GDS) in London, on Queen Elizabeth Olympic Park (previously hosting the London 2012 Paralympic Games). It was attended by 1000 delegates from Governments, Donors, Private Sector Organisations, Charities and Organisations of Persons with Disabilities and resulted in 170 sets of commitments across the themes of: Data disaggregation, Inclusive Education, Routes to Economic Empowerment; Women and Girls with Disabilities; Conflict and Humanitarian Contexts; and Harnessing Technology and Innovation – which led to the formation of a Global Partnership on Assistive Technology with nine founding partners (UKAID, USAID, WHO, UN Special Envoy Office (UNSEO), UNICEF, Clinton Health Access Initiative, Global Disability Innovation Hub, Government of Kenya, Chinese Disabled People's Federation) (FCDO, 2018)

Notes from my own diary at the time, reflect that the conference brought the issue of Assistive Technology to the forefront of the global agenda. The Rt. Hon. Penny Mordaunt MP (then, UK Secretary of State for International Development) noted AT access in her opening address to the event (in sign language, which she had learnt), and in the UK Parliament too, for the first time. This was a significant milestone in building the global momentum toward increasing global action on AT, launching both ATscale, and AT2030 as we shall see below.

Progress against commitments made through the *Charter for Change* was tracked one year on to find work ongoing on 74% of the commitments and 10% already completed. Sixty eight percent of respondents to the questionnaire thought that GDS18 had made it easier for their organisation to work in a more disability inclusive way. GDS22 is planned for Norway in February where further progress will be tracked, and commitments made. This moment is relevant as the starting point of building global momentum on AT, and the start of new actors entering the field.

2.3.3.5 AT2030 - Testing 'what works'

GDS18 launched AT2030, the programme (led by GDI Hub) within which this work is funded. AT2030 was a ‘quick start’ programme designed to ‘test what works’ to get AT to the people that need it around the world. Through a partnership involving more than 70 partners, including country government, WHO, UNICEF, CHAI, local partners and others, in more than 30 countries, the £40m investment is testing new mechanisms of getting AT to the people that need it around the world through four themes: data and evidence, country implementation, innovation and community capacity support. So far, the programme has reached 25m people. AT2030 is currently compiling data on ‘what works’ to get AT to the people that need it around the world and has contributed 150 background papers to the Global Report on AT.

2.3.3.6 AT scale – the Global Partnership for AT

A second key initiative which resulted from the GDS was ATscale, the Global partnership on Assistive Technology, established with a *“vision to enable a lifetime of potential where every person can access and afford the life-changing AT they need”* (ATscale, 2020)

The mission of the partnership is to be cross sector, to amplify work and coordinate and mobilise stakeholders with unified strategies to increase availability of and access to affordable and appropriate AT. Their strategy, published in 2019, sets out the strategic priorities of ATscale, and hence *the* global policy priorities.

Global Partnership on AT strategic priorities

- *Generate evidence and data;*
- *Spark Innovation and new solutions;*
- *Drive affordability and availability (through market shaping);*
- *Strengthen policy, systems and implementation;*
- *Build capacity and partnership (of AT user, countries and AT workforce); and*
- *Galvanise investment and political support*

(ATscale, 2019)

I will turn now to the research and evidence base for AT, organised by these areas set out in the Global AT strategy. Each section below will provide an overview of evidence and current policy challenges.

2.3.4 AT trends against the themes of the Global AT Strategy by ATscale.

2.3.4.1 Data and Evidence

Because this whole literature review presents data and research evidence on AT, this section looks at trends. Historically, studies have tended to focus on AT in terms of the technology or its novel application for a particular group of people (e.g., (Barbareschi and Holloway, 2020; Smith and Bagley, 2010). Increasingly a health systems and policy approach is being taken (as set out below), and partnerships have started to feature in the literature (Layton et al., 2018). Some important work on access to education and livelihoods (e.g., (Smith, 2000) will continue and remains necessary. However, a search revealed nothing specifically tackling AT from the perspective of supporting access to justice in the Global South context. Much of this work originates in Disability Studies, some in Engineering, some in Human Computer Interaction[4], some in social policy, yet often the social/ policy concern (which may address some aspects of justice) does not interact with the engineering approach (which is usually where AT is prioritised and designed). A recent survey of two major Human Computer Interaction conferences (ASSETS and CHI) found: "*In the nine years of ASSETS conferences after [2010] there is less than a handful of papers [four] that have intersections with disability studies scholarship. A scan of the titles and abstract of the past three years of CHI papers revealed that out of the more than 2000 papers, the number of papers that primarily build on Disability Studies is near* zero" (Ghai and Reddy, 2020).

Work related to the current health crisis has found a disproportional impact on disabled people of COVID-19 (Smith et al., 2021) with evidence from a rapid study backing this up (Smith et al., 2020). In the UK, it is well documented that disabled people have borne the brunt of the crisis, and now global partnerships are calling for vaccine equity for disabled people who are being deprioritised in many countries. A recent Lancet study also found that COVID-19 will impact provision by increasing the reliance on peer support and moving toward digital devices (Khasnabis et al., 2020). There is an increasing trend to view innovation in AT, as part of a system-wide intervention, rather than ad-hoc 'inventions' as the section below will now describe.

2.3.4.2 Spark Innovation and New Solutions

Innovation in AT has tended to mean new tech, historically but that is changing. Historically funders, interested partners, donors, students and techies themselves have been focused on the frontier of fundamental tech development. But in reality, innovation in the AT space - if you have a goal of getting more AT to more people - is actually about innovation in the policy, system, last mile, market, and value chain around the (largely existing) product. Put simply, new products will not solve the problem. A new paper on Innovation commissioned for the Global Report on AT uses a systems mapping model (MacLachlan et al., 2018) to review the literature. This systematic review, which is part of a background paper for the World Report on AT (Holloway et al., 2021), demonstrates that whilst there are several studies which support product level innovations, there are fewer focussed on the provision system and relatively few innovations focussed on the supply. This focus on the product level without a link to how the products will be provided or supplied can be seen as limiting innovation in AT.

To overcome these limitations found across AT innovation the authors of this systematic review recommend a strategy of *Open innovation* for the AT sector. Open innovation is defined as the use of "*purposeful inflows and outflows of knowledge to accelerate internal innovation and expand the markets or external use of innovation respectively*" *(*H. Chesbrough et al., p. 1, cited in Holloway et al, 2021)

Open innovation also means allowing for start-ups to have easy access to more established companies in the value chain, to academics, technical assistance and to sector experts. This is recommended instead of the idea of all the knowledge being ringfenced in a single institution or company. Open Innovation as an approach suggests that partnerships are the

---

[4] HCI researches the adaptation of computing and digital devices for disabled people alongside widening usability of all digital products and services through accessibility and universal design.

answer, at least in part, with each actor playing to their unique strengths (ibid.) and sharing what they know in the public good.

This Innovation Background paper (ibid.) considers a suggested mechanism for encouraging open innovation – the creation of networks where ideas are more easily shared and developed, to be achieved through as accelerators, challenges or incubators, as well as by larger companies simply being more open to receiving external ideas. The work argues that the provision of AT under the current mechanisms does not work and whilst system strengthening will get part way to overcoming the gap, there is also an opportunity for novel approaches to help close the gap more quickly.

It is exactly the assumption that innovation can disrupt the AT space and get more products to more people more quickly, that has motivated many social entrepreneurs to enter the market recently; the rise in incubators, accelerators and industry collaborations around AT is evident. The Innovation Background paper (ibid.) found a number of case studies of accelerators, the most notable are Remarkable (Australia), Social Alpha (India) and Innovate Now (Kenya). There are subtle differences between these initiates which are detailed in Table 1.

Table 1: early-stage innovation programmes which seek to use an open innovation approach, reproduced from Holloway et al., 2021.

Programme	Details (adapted from Holloway et al., 2021)
Social Alpha (India)	• 16-week accelerator programme equip early-stage start-ups with: knowledge, skills, tools and seed funding • Focus on social impact and business viability • It also offers a mentor network, co-working space, as well as disability-sector expertise.
Innovate Now (Kenya) led by GDI Hub under AT2030	• Africa's first Assistive Technology Accelerator and hosts AT start-ups from three to six months. • It uses an innovative active learning model to upskill AT innovators in entrepreneurial, product and business topics, which are then tested in live labs with academic support for study design. • Model combines mentorship, workshops, guest lectures, and hands-on disability expertise to help AT start-ups to reach product-market fit and become investable and scale-ready.
Remarkable (Australia)	• 3-tier approach designed to nurture AT entrepreneurs from their lab to their market journey. • Connects innovation and investment ecosystems to drive financial and operational support for start-ups. • Links to providers of risk capital and technical expertise, incubation labs

The Innovate Now initiative is linked to the AT2030 programme and as such has access to the data and evidence teams within academia to help evidence the benefits of AT. This evidence is beneficial at several levels: for the start-up in gaining future investment, for the programme in demonstrating impact, and for the sector in demonstrating value. Early research with innovators helped drive the design of Innovate Now. Two products were tested in the field in Nairobi – 3D printed wheelchairs and a novel prosthetic device. These early studies demonstrated the value of a user-centred product which is locally made, has much higher value to the user and is trusted intrinsically by the medical team as they feel more confident in subsequent ability to repair (Barbareschi et al., 2020a). The value of the wheelchair for example was seen not only in the function of the wheelchair user but also in their self-worth; they were proud to use a wheelchair they had been integral to creating (Barbareschi et al., 2020b).

These studies also demonstrated the gap between small scale testing and securing a full trial and investment. The gap – the need for a financial investment at scale for ventures was demonstrated and drove the creation of the world's first AT impact fund. This gap was also evidenced in the systematic review which concluded the need for a new financing vehicle which goes beyond the remit of an accelerator and would help bridge the gap between accelerators and traditional impact or venture capital funding. Currently the AT impact fund is the only such vehicle and is only able to deeply grant capital in its current structure, which would seem, given the evidence, to be a limitation.

Rise of robotics, AI and 'home-everything'

It would be remis not to discuss the global rise in the number of patents being filed in assistive technology focussed on emerging technologies such as robotics, artificial intelligence (AI), which also relates to the home as a base for rehabilitation, tele health, tele working ('home-everything') - all of which need to be inclusive for disabled people. These trends are clearly demonstrated in the recent World Intellectual Property Organisation report on AT. The largest growing market is the built environment (42% average growth rate), which represents technology such as assistive robots, smart homes, and smart cities). Other domains which are rising include vision, self-care, mobility, hearing, communication, and cognition. However, across the board only 17% of patents make it to market (WIPO, 2021). This again demonstrates the problem with translation of products to the market. However, a greater issue remains – as technology advances, we are still left with most technology only reaching a very small number of people. The one technology which has consistently bucked this trend is the mobile phone, as highlighted in an earlier section.

2.3.4.3 Drive Affordability and Availability (through Market Shaping)

Many countries lack the large-scale product production and procurement that would be required to meet the need for AT (MacLachlan, 2019). Meanwhile, demand is latent and information asymmetry (in the form of the principal – agent split) represents a genuine market failure (Holloway et al., 2018) resulting in high prices for a poor choice of low quality products in many countries. Loosely, market shaping refers to strategic, (usually) public sector intervention and/ or investment, made to overcome inefficiencies in the market (and the system around the market) which prevent (usually, public) goods from reaching the people that need them (USAID, 2014).

Oft cited examples of successful market shaping strategies are on Anti-Retroviral Treatments (ART) for HIV (Waning et al., 2010), malaria, and diarrhoea treatments, and immunisation. Some interventions designed to bring a high price, low volume market equilibrium, toward a lower price, higher volume market equilibrium saw a price drop of 30-

50% (Dabas et al., 2019), others were higher. USAID highlighted the most commonly used market shaping strategies in their primer of the same name:

> *"Market shaping interventions typically use three types of levers:*
>
> *Reduce transaction costs – Lowering structural hurdles to market interactions, such as by simplifying, smoothing, or rationalizing orders without money necessarily changing hands.*
>
> *Increase market information – Generating new data, aligning existing analyses, or improving the visibility of existing data to reduce asymmetries of information.*
>
> *Balance supplier and buyer risks – Transferring financial risks to donors/purchasers to encourage existing and new suppliers to operate more actively in the market."* (USAID, 2014, p.6)

A paper presented to GREAT summit in 2019 considered the role market shaping could play for AT. The authors argued that "Market shaping interventions can play a role in enhancing market efficiencies, coordinating and incentivizing the number of stakeholders involved in demand and supply-side activities. Across health sectors, market shaping has demonstrated its potential to enhance national governments' or donors' value-for-money, diversify the supply base, and increase reliability – ultimately increasing product and service delivery access for end users. These market shaping successes in other health areas have led practitioners to hypothesize that market shaping could also be applied to assistive technology markets" (Savage et al., 2019).

Notes from my research diary in 2018 -2019, reveal the extent to which this market-shaping approach has driven traction within the donor input to the AT space. Especially, in the discussion and debate at the highest level where the focus of the core strategies for ATscale and GReAT were discussed with UK aid and US aid. It is difficult to disagree with the idea of getting more products to more people for less cost – in fact it would be silly to. But I now reflect that the intention to work on market shaping for AT was/ is based on two fundamental beliefs, that 1) evidence on vaccines and essential medicines could set up a model for AT market shaping that was similar, and 2) a normative understanding, by some donors in particular, that market-based aid solutions are superior because of an adherence to a neo-liberal politics and socio-economic paradigm.

Since the first point remains to be proved, or tested yet, that leads us to consider the second point in more general terms, looking at the role of neo-liberal assumptions in aid more generally, before returning the key points to the AT debate.

Global Value Chains and Market-based Development

The approach to shaping markets and using increasingly disparate global value chains to drive development is now firmly rooted in mainstream multilateral agencies approach to supporting low and middle income countries grow (Ambos et al., 2021). The 2020 World Report on Development – entitled *'Trading for Development in the age of Global Value Chains'* – is unequivocal:

> *"Do GVCs still offer developing countries a clear path to progress? That's the main question explored in the 2020 World Development Report. And the answer is yes:*

> *developing countries can achieve better outcomes by pursuing market-orientated reforms specific to their stage of development." (World Bank, 2020)*

This focus on trade as an element of development progress is also reproduced in bilateral and donor agencies, for instance with the UK recently merging its Foreign Office with its Development Office in order to: "mobilise all of our national assets, including our aid budget and expertise, to safeguard British interests and values overseas", said the Prime Minister, Boris Johnson in the press release announcing the move (Prime Ministers Office, 10 Downing Street, FCDO, 2020).

Other authors have commented on the plethora of private aid agencies who have entered the space of development aid; some have indicated that this leads to a focus on the more middle-income countries where 'impact' can be more easily delivered (Kock et al, 2007). Recent scholarship considering the role of US government strategies identified that though "from the American people are the words stamped on the US govt aid packages, yet American aid as a public good is increasingly being delivered by for-profit firms" (Brunt and Casey, 2022 p 55), pointing out that this trend changes both the composition of stakeholder engagement and the flexibility and interchangeability among vendors. This leads one to conclude, fewer specialists with contextual experience are needed.

One note in my research diary is particularly relevant here. A meeting in 2019 resulted in a presentation on market-based approaches to Aid (and potentially AT) delivery, as 'preferred' by the donor in question. The presentation offered no critical analysis and resulted in an admission that the payment on outcome performance approach brought some delivery risk as some smaller, local organisations had faced financial concerns, and been incentivised to target easier impact. It was also shared that the cost per unit was higher overall. Yet, unequivocally it was best. This was the most explicit of these discussion in all five years of my work in this sector, more usually the assumptions are left implicit.

To conclude this section then, I do not argue that there is not a role for market shaping of assistive products. Recently UNICEF, supported by AT2030, has been able to do market deals for hearing aids and wheelchairs putting quality products in their catalogue at a lower price. This is a huge step forward. However, I do suggest that it must be acknowledged that some elements of incentivisation of AT procurement decision making is fuelled by the socio-political-economic paradigms from which they emerge, thus underlining the point made in section 2.2 on the neo-liberal policy approach to disability in general.

The next section of the AT global approach is about strengthening systems on policy support.

2.3.4.4 Strengthen Policy, Systems and Implementation

Both before the ascension of market-shaping approaches, and interwoven within it, systems thinking has come to dominate the frontiers of the global policy and research discourse on AT. This is beyond, but intrinsically linked to, the importance of AT as a key component of Universal Health Coverage (UHC), which was first recognised by the World Health Assembly (WHA) on 26th May 2018, when it unanimously passed resolution 71.8 'Improving Access to Assistive Technology' (World Health Organization, 2018). Subsequent content analysis of responses to the resolution by Member States concluded with a helpful definition of the systems-thinking requirements in this context, it summarised:

> *"the complexity of factors [involve] demonstrates the importance of an AT systems thinking approach; that is, the development and application of organised knowledge, skills, procedures, and policies related to assistive products. AT systems thinking will be essential for AT to be effectively deployed as a pillar of universal health coverage".* (Layton et al., 2020a)

This compliments and underlines the definition of AT, offered by WHO (presented at the start of this section) and follows the findings of the first GREAT summit, in 2017, which were encapsulated in a journal article by its Chairs. They suggested that it is helpful to view the AT landscape as an *'"open" system, that can evolve and adapt'* recommending "*the adoption of a stronger systems thinking perspective within the assistive technology field should allow for more equitable, more resilient and more sustainable assistive technology across high, middle- and low-income contexts and countries"*(MacLachlan and Scherer, 2018, p. 492).

The lack of systems-thinking in the AT sector has been suggested as a major barrier in access to AT, especially for those in lower resourced settings (MacLachlan, 2019). Further in the same paper, the author highlighted a model, *'the SMART thinking matrix'* of AT systems thinking which divided the system into three levels: the micro (user), meso (service-provider) and macro (national/international). The framework highlighted the provision of assistive technology across these system levels and across three levels of market: minimally, moderately and optimally functioning and was later adopted by a major research initiative including a systematic review on Innovation around AT for the world report (Holloway et al., 2021).

The SMART thinking matrix (ibid.) is proposed to aid a stronger approach in low income contexts, and to better leverage market-shaping with an explicit aim to support a stronger, fairer and more resilient market for AT in poorly resourced settings; thus it posits AT as a bridge between what people are potentially capable of and what they are actually able to do, to further the 'parity of participation' (Fraser, 2000) of AT users themselves (ibid.). This brings us to a discussion on community capacity at AT provision.

2.3.4.5 Build Capacity and Participation (of AT users, countries and workforce)

There is very little research which looks at the role of AT in building the capacity of users to participate, the aspect of this priority that most concerns this study. As one recent paper found, there remains very little evidence about the impact of AT on access to participation in citizenship practices, and even less looking at the very poorest persons with disabilities in the global south though (MacLachlan and Scherer, 2018).

There are some notable exceptions though, with emerging work that considers the role of the informal market in provision of AT offering a reflection on the 'adequacy' of AT products which might be affordable and available to poorer communities (Walker and Tebbutt, 2022). This emerges from engagement undertaken by AT2030 mapping community provision, cross-referenced in some detail later in this thesis. Similarly, in Kibera (a large informal settlement in Nairobi) (Barbareschi et al., 2020a) explored mobile phones as AT by people with a visual impairment who reported strong reliance on social networks of human support. (Sackey, 2015) considered AT as part of political participation in Ghana, and (Opoku et al., 2017) did similar in Cameroon. Yet, little global traction from these few studies has emerged, in part because while it is well documented that participation in the activities one values has tremendous development benefit as means, as well as, ends of development

(Sen, 1999), it is not often applied to AT which 1) tends to be abstracted to the technology itself (device) and the technologists who provide it, or 2) is seen only as a means to a productive end (education or work). This is exemplified if we look at the current global approach to manifesting political support through return-on-investment modelling.

2.3.4.6 Galvanise Investment and Political Support

It is by now well established that disability and poverty are cause and consequence of each other (Banks et al., 2017) and AT is a one potential tool for independence, a potential factor in the route out of poverty. A recent study for the Global Partnership on AT highlighted that a family needing access to AT in an LMIC could see their income increase by as much as $100,000 on average, over a lifetime if that AT was available (ATscale, 2020). The same report showed that if the four main Assistive Devices were provided freely, a total yield of more than USD 10 trillion could be expected (and over a billion Quality Adjusted Life Years) due to the 'ripple effects' from increased productivity and reduced welfare expenditure. Overall, a 1:9 return on investment was estimated for AT (ibid.).

As important as it might be seen to be, to increase the focus of global aid donors on AT provision, by those with good intentions (and less so), there is still the question of whether this 'buys into' a model of the economy which offers value to the productiveness each person can provide, aiding their performance in work or education towards a great economic growth. Yet, to hear the first-hand stories of what it means to lack AT, it is necessary to go to the community level where the impact of lack of access is much greater than the value of economic contribution; researchers found that without AT "children left out of education; adults excluded from earning a livelihood; women (particularly, but not exclusively) unable to lead independent lives; and older people unable to take part in their communities" (Holloway et al., 2018, p.2). AT2030 has collected some of these life stories as part of the programme (AT2030.org/impact stories). When delivered appropriately, with quality products and wrapped around services for fitting and rehabilitation, AT can be empowering, cost-effective and a key enabler of achieving the SDGs (Tebbutt et al., 2016).

2.3.5 Thinking critically about AT interventions

2.3.5.1 The 'able disabled' and expectations of 'usefulness'

Some in the disability movement have criticised the panacea of Assistive Technology, heralded for its ability to 'fix' individuals and make more 'normal' their bodies and experiences. While it has been stated that the London 2012 superhuman campaign led by British TV station and Paralympic Broadcaster, Channel 4, did much to challenge the stigma around disability and move the debate forward (Austin, 2021), beyond the profile of the main athletes (Smith and Thomas, 2012), the example of high tech prosthetics used by super fit, super human athletes has been criticised for excluding disabled people who are not 'super human' and just 'ordinary' like the rest of the planet. Snyder and Mitchell related this to the fetishization of other identities, providing a tight space within which a group might be 'allowed' to 'fit'.

> *"Like Paul Gilroy's identification of the black, buffed, hyper-athletic bodies of African American athletes now commodified and traded across the Atlantic, the newly rehabilitated, fetishized disabled body comes replete with racialized, classed,*

> *gendered, and sexualized characteristics of its own—features that seem to make new inclusivism a radically individualist and ever-accomplishable horizon for disabled subjects"* (Snyder and Mitchell, 2010a, p. 118).

The Paralympics is often cited as the example for this, for instance with reference to '*Murderball*' the documentary about wheelchair rugby that is about the US Paralympic team member, Mark Zupan, who received recognition from President Bush as a star (McRuer, 2010). The message was that if you can be exceptional at sports you can be accepted. AT is core to Paralympic sport and to the idea that with AT, 'dis-abled' people can become 'able'. (Oggero et al., 2021) found that over 80% of the Paralympic medals throughout the last 50 years have been won by the Global North countries in which athletes have access to AT, connecting the two aspects (success and participation in paralympic sport, and access to AT) clearly. Mladenov cited this expectation of performance by disabled people (be it sporting or socio-economic) as intrinsically linked to the economic system, as we discussed in 2.2. He argued:

> *"performativity is the ontological, ethical and epistemological principle of postmodern capitalism, where torn safety nets and rising indebtedness coalesce with new and emerging technologies to subject people to ever increasing pressures for performance enhancement."*(Mladenov, 2020, p. 52).

I read from this a critique of the assumption that AT is used to enable performance as valued in a capitalistic sense. Also explicit in the work is a criticism of the notion of value as assigned via economic contribution.

This is also related to how the value of AT is accounted for in terms of return on investment.

Some Disabled People's Organisations have historically tended to make the case, following the social model of disability, that AT is simply one element of levelling the playing field, like inclusive access or reasonable adjustments. Given the AT's association with 'fixing the person' (the Medical Model of Disability section in 2.2), it has been historically split from the priorities of the disability movement in many cases. The empirical chapters will go into this in more detail in discussion with some of these leaders. But while it is necessary to hold this critical challenge, it is also important to retain focus on the reality for disabled slum dwellers, the focus of this study. Much of this debate is live (especially in the Global North) but does not factor so significantly in the practical everyday realities of poor disabled people in the Global South.

Following Shakespeare's (Shakespeare, 2013) thinking: if you need to collect water, or make a livelihood to enable your family's survival, and a walking stick would help, the emulation of 'normal', 'able' bodies through the technical assistance of the AT is almost certainly not at the forefront of your mind. Similarly, the CA, would suggest that AT is important to aid people to do the things that are important to them, not to serve as a spectacle of what is theoretically acceptable in disability terms to other people. Basically, I make the case that AT is a strategic and essential aid to participation of all types not simply a device to fix a person. That said, it is not intended that the strategic and long-term impacts of structural oppression are ignored in favour of a focus on the everyday need to survive, quite the opposite. Rather the proposition being posited is that both AT *and* work to address these oppressive structures are required, but AT is a fundamental necessity of the latter. The choreography of these interventions remains the source of much debate, as we shall see.

2.3.6 Conclusion

This section has taken us through the current research and policy position on AT, the many relevant initiatives currently being undertaken, and an exploration of how new and emerging technologies might become, or already have become, ubiquitous – like the mobile phone.

It is precisely the opportunities AT opens up which now begin the discussion about participation to make claims and take action. It is to this participation we now turn, taking a closer look at the context of disability, urban poverty and citizenship.

Summary of Key themes identified in this section with relevance to the framework

- AT is defined globally by the WHO as a priority-products plus systems approach, and this definition is adopted here;
- Mainstream accessible tech - like mobile devices - is increasingly providing the function of AT (Holloway, 2019) and can be used for building social movements (Milan, 2013) but not without limits;
- Technology is not uniformly available and is provided within a neo-liberal paradigm which includes the increasing marketisation of Aid interventions (Kohl 3rd et al., 2012);
- A growing and vast body of work on AT interventions is strengthening systems and promoting investment, considering market shaping perspectives;
- AT has not always been a top priority for disabled people organisation due to the association with the Medical Model of disability, but it remains important;
- AT is a strategic enabler of all types of participation.

2.4 Disability, Urban Poverty and Citizenship

2.4.1 Introduction

The representation of the voices of disabled people - as academics, researchers or even participants within research - is far too limited (Holloway, 2019). Hence the lived experience of disabled people - especially disabled women and men living in poverty - is often poorly catered for by theory or ignored beyond useful test case. In technology the term ‘disabled people’ is often represented as an ‘extreme user’ by who to trial a product’s broad use, rather than designer or agenda setter. This section then, begins to map out, and consider what it means to understand a notion of citizenship and participation, with a particular focus on disabled women and men living in urban poverty, where possible drawing evidence from informality in the Global South, though it is necessary to state the paucity of such data up front.

A caveat: the citizenship literature is vast, historically rich, and in places densely abstract, philosophical and theoretical. Construction of disability within this space is to some degree an important context, and is summarised below; however, this is not the core intention of my work. Instead, a practical lens is intended and applied, given the research questions and case study I address. Of particularly interest is considering how the collective capacity for aspiration (Arjun Appadurai, 2004) and recourse to cultural (Holston and Appadurai, 1998), and inclusive (Kabeer, 2005) citizenship practices can play a role in creating innovative spaces where citizenship claims can be generated and made (particularly in terms of how we overcome the destructive and very real impacts of stigma experienced by disabled women and men). This topic is vast and well-studied by social development practitioners and thinkers, yet the nature of the debate is complex and very few simple definitions fit neatly. Hence the section below raises many topics of interest for the investigation but settles very few of them. Nonetheless, core principles to inform the framework for that, are drawn out in the concluding section where a short summary is presented.

2.4.2 Disability and Urban Poverty

As set out in section 2.1, despite the fact that poverty and disability indicators are proxy and weak, it is significant that all evidence suggests disabled people fare worse than other people and are left behind as countries develop. In addition to income poverty there is also well documented evidence suggesting that the health of slum dwellers adversely impacted by poor living conditions and lack of access to water and sanitation (Corburn and Riley, 2016). As Corburn and Riley argued, “slum conditions are fundamentally a manifestation of institutions underinvesting in housing, infrastructure and life supporting services for the urban poor, not an inevitable consequence of urban growth” (ibid., p.3). They also highlighted the importance of increasing the role of the urban poor and their organisations in slum health action research as they demonstrated that when intervention agendas are set without a meaningful participation role of slum dwellers themselves, they often fail to improve health and wellbeing outcomes due to lack of knowledge about what is needed (ibid., p.275).

It is necessary then, to consider the construction of our understanding of poverty before undertaking this study. To begin, though I note that extreme income poverty was reduced under the Millennium Development Goals by half (UNDP, 2017) it remains the number one Global Goal (United Nations, 2015) with more than 700m people still living in extreme poverty before COVID-19, and figures post-COVID-19 are yet to be released at the time of writing. We know that ‘poverty is many things, all of them bad’ (Arjun Appadurai, 2004, p. 68):

> *“Poverty dehumanises and erodes the confidence of an individual. Therefore, it becomes necessary that all measures taken to address poverty must be grounded in human rights”.*(Durojaye and Mirugi-Mukundi, 2020, p. viii)

In everyday parlance poverty tends to be used to refer to the lack of material wealth, but according to the World Bank– influenced by the work of Sen (Fukuda-Parr, 2003; Sen, 1999) and others, poverty is described as deprivation of wellbeing. Since 1990 this *“shift [in]the focus on development economics from national income accounting to people centred policies”* (Ibid., 2003, p.304), the UN has largely continued to speak the language of human wellbeing following Sen, viewing development interventions as framed through this approach. It is worth reproducing Sen’s core Capability Approach (CA) argument which is central to this study:

> *“Development can be seen… as a process of expanding the real freedoms that people enjoy. Focusing on human freedoms contrasts with narrower views of development, such as identifying development with the growth of gross national product, or with the rise in personal incomes, or with industrialisation, or with technological advance or with social modernisation”*
>
> *(Sen, 1999, p. 3)*.

Following this view, development and poverty reduction requires the removal of major sources of ‘unfreedom’ including ‘*social deprivation, neglect of public facilities and intolerance’* (ibid.). Adopting this approach and considering further, Martha Nussbaum reminds us “(economic) growth is a bad indicator of life quality because it fails to tell us how deprived people are doing” (Nussbaum, 2003, p. 33). People are viewed in the Capability Approach (CA) as both the beneficiaries and the agents of change, about whose fundamental capabilities (what people are capable of) and functioning (what people actually do) development should be concerned. As Frediani explained, “the core characteristic of the capability approach is to de-emphasise an exclusive preoccupation with income-led evaluation methods and to focus more generally on the ability people have to achieve the things they value” (Frediani, 2007, p. 138).

Sen and Nussbaum, disagree on whether a set of essential capabilities should be available to everyone, and though there is not space for a further debate here, it would certainly be interesting to consider whether those in the greatest condition of exposure to the absence of capabilities (poor disabled people perhaps?) might actually benefit most from such a list as that produced by (Nussbaum, 2011). Yet, one thing is certain, both agree on the central role of agency and participation, and it is the central argument which sets up the core question here: how is AT necessary for participation, beyond the functional activities of everyday life? How does AT aid the disabled people to do the things *they* value? Thus, to this point we now turn.

2.4.3 Agency and power

If agency and participation are fundamental to development objectives (‘as the primary means as well as end’ (Sen, 1999), but poor people are poor ‘because of others’ (Wood, 2003), and poverty is relational (Mosse, 2010), then elevating the agency and participation of traditionally excluded groups becomes a necessary factor in changing the status quo. Hence in setting out to explore whether technology can in some very real sense offer hope of practical support and in some certain practical aspects of daily living an understanding of agency and power is important. As White argued:

> *“Participation has the potential to challenge patterns of dominance, and it may also be the means through which existing power relations are entrenched and reproduced…Participation may take place for a whole range of unfree reasons. It is important to see participation as a dynamic process and to understand that its own form and function can become a focus for struggle”*(White, 1996, p. 6).

(Green, 2012, 2008) provided a detailed, practical and comprehensive overview of poverty and power (drawing of course on core scholarship such of (Cornwall, 2002; Gaventa, 1982; Gaventa, John, 2004), paraphrased loosely he summarised power as *visible* (e.g. political power, CEOs), *hidden* (behind the scenes; lobbyists, corporations), and *invisible* (insidious power within people, which is the force that causes people to internalise assumptions and limitations). Green posited that they are all forms of power which are necessary to understand in order to comprehend how change happens (Green, 2016, 2008).

Rowland’s (Ibid., p.33) work on women’s empowerment in Honduras offers a feminist perspective highlighting how power can operate in practice. She found four types of power: *Power within* (personal self-confidence and sense of rights and entitlements), *Power with* (collective power through organisation and solidarity), *Power to* (meaning in effect choose and the capability to divide and carry out actions), and *Power over* (the power of hierarchy and domination). The literature search reports few if any examples of this analysis for disability in the Global South context. These categories are not bounded but fluid, following Chambers’ ‘uppers’ and ‘lowers’ (Chambers, 1997) - people can have mixed and changing identities or roles in different circumstances.

Green argued that power does not have to be a zero-sum game, especially if viewed long term. Often change is prevented because of institutions, (poor) ideas, or interests (not always malign)(Green, 2016). However, strategies which consider alliances, collective approaches and cultural events can help (Green, 2008). It is now helpful to consider how this relates to the discourse on citizenship, and particularly the inclusive models that have been developed by those seeking to empower disadvantaged or traditionally excluded groups.

What is emphasised by this discussion is a point to which I shall return in the final part of this sub-section; the notion of power as a mechanism to set the agenda for debate and action, following Lukes (Lukes, 2005). This notion is relevant particularly, when considering the impairments to agenda setting disability identity can present. Especially when one considers the role of agency in both individual, autonomous or potentially as agency, supported by others. I will now turn to this very specific discussion in relation to disability identity.

2.4.4 Disability, care and non-autonomous agency

Considering the debate about models of disability set out in 2.2, it is clear that it is historically the case that disabled people's agency has been undervalued and overridden, and this continues to be so in many countries and on many occasions. However, in the case of disability, some authors have suggested that agency should be seen as more than an individual pursuit; we may wish to consider the role of supported or non-autonomous agency.

In a recent chapter on methodical challenges of intersectional research in the same urban context as this study, Walker and Ossul-Vermehren suggested that while the inclusion of diverse voices such as those of disabled people is crucial, it can also be reductionist, prescriptive and divisive at the expense of revealing shared relations (Walker and Ossul-Vermehren, 2021, p. 167). Further they highlighted a very valid point about intersectionality – not assuming that disabled people form a monolithic group with identical interests, yet still making a case for adopting (reflexively) a disability category in order to reveal pervasive structure of inequality and addressing issues of stigma (ibid.). The proposed 're'-construction of disability gives valuable pointers to the pitfalls of tokenism, on the one hand. On the other hand, after centuries of historical oppression such re-construction will require a great deal of thought, leadership by disabled people, and structure shifts; it cannot be assumed lightly.

This highlights the importance of understanding agency in relational as well as in autonomous terms, and of considering the extent to which a reliance on autonomous relations provides for emancipatory solutions.

One such area which has been, on the one hand, vital and, on the other, historically problematic, is care. I was clear in the methodology, that the care in general is out of scope for this work. However, care as an enabler of agency is a reality for many disabled people. Some of the evidence from Walker and Ossul (Walker and Ossul-Vermehren, 2021) identified the need for care as a support to disabled people in participation, which was a reality for some. Walker (2022) went further by highlighting the tension between care as a necessity and as an impediment to autonomy, and recognising there is often power asymmetry between care givers and care receivers which does not facilitate the agency of disabled people.

(Piepzna-Samarasinha, 2018) went one stage further. She highlighted that the institutionalisation of many disabled people, formally in 'sanitoriums' or 'charitable institutions' or informally in what might be called day centres or even 'the home' for the purposes of care, is a product of colonialisation, invented in the era of modern capitalism; this has often been the location of a lack, at one end, of the spectrum and violent abuse at the other (ibid.). This heritage is heavy and warrants a deep and longstanding exploration with the voices of those with direct experience leading the charge. For the purpose of this work, I acknowledge that the relationship between disability and care is vital then, but that the history and depth of the debate is complex. I do not attempt to answer these questions here – but rather I acknowledge that further work might consider in more detail the role of non-autonomous agency, or rather supported autonomous agency, as important and interesting.

I will return to the idea of relational social arrangements at the end of the chapter, but first I want to give space to the debates about the spaces of citizenship in which the application of agency in the form of participation takes place.

2.4.5 Disability and Citizenship

Approaches to citizenship determine and are somewhat (to a much lesser extent) determined by disabled people and disability movements. In the next sub-section I consider the core contestations of citizenship that have dominated political discourse and practice for centuries, with increasing focus in the last two decades on what inclusive models of citizenship should comprise. Yet, the *“idea of citizenship is nearly universal…what it means and how it is experienced, is not”* (Kabeer, 2005, p. 1). Contestations vary in response to local context, demographic and intersectional issues, spatial locus and of course theoretical perspective, but often what remains constant is a failure to address issues of disability effectively either theoretically or with practical application.

2.4.5.1 The Classic Liberal model

The classic liberal model of Citizenship sets out the rules – written and unwritten – under which consent for governance is given; the ‘social contract’ (Rousseau, 1964). With its focus primarily on civil and political rights which are non-conditional on the fulfilment of prior duties, the Classic Liberal Model sees the state as obligated to protects its citizens de facto - regardless of their actions. This model is paternalistic and exclusionary, and is not consistent with the theoretical perspective on disability due to its assumptions about what ‘normal’ is (Nussbaum, 2006) see more in section 2.5). It is critiqued by (Holston and Appadurai, 1998, p. 1) because it “links citizenship and nationality to establish the meaning of full membership of a society”. In time, within the economic context of hegemonic capitalism, a neo-liberal model emerged.

2.4.5.2 Neo-Liberal Model

The Neo-Liberal Citizenship model relies on an understanding that the duties of the citizens come prior to rights. In this model the state role becomes an unblocker of access to the ‘freedom’ of market engagement for individuals. This definition of citizenships valorises access to economic self-reliance and downplays the notions of social identity.

Neo-Liberal responses to citizenship have tended to bring in a focus on economic, political and social rights, but with a strong focus on ‘earned’ protection. This has played out strongly around welfare agenda in countries like the UK, where concepts of the ‘deserving’ poor have been used to justify who does and does not receive support. Some of these policies have been devastating for groups excluded from being considered ‘deserving’ (Briant et al., 2013; Garthwaite, 2011; Warren, 2005). Some scholars have argued that the ‘welfare to work’ agenda in the current neo-liberal trend has tended to disregard structural barriers such as labour market exploitation, or factors that limit social mobility (Mladenov, 2017b) and ‘smuggle’ in unfreedom (ibid.) under the guise of that welfare approaches which favour a productivist morality (Mladenov, 2015c). I will come to discuss productivism much further.

2.4.5.3 Disability-exclusion from citizenship through ablenationalism

Ablenationalism was coined to describe treating people with disabilities as an exception (non-normal), and the extent to which this valorises the non-disabled norms of inclusion as a qualification for citizenship (Snyder and Mitchell, 2010a). Snyder and Mitchell (2010b, p.114) argued: "Whether nation-state of market-supplied, ablenationalism's calculated provision (and non-provision) of services based on principles of detecting and qualifying bodies as 'too impaired' for meaningful labour underscores the degree to which the category of 'deserving poor' is a highly guarded space of ostracization".

As (Snyder and Mitchell, 2010a) suggested, and as we have considered elsewhere, perhaps a value of transgressive re-appropriation (such as Queer or Crip theory) can serve as a motivator of resistance, political commitment and disruption in this context.

I now turn to the models which address citizenship from a perspective of activism and social justice by developing more inclusive approaches.

2.4.5.4 Inclusive Citizenship

Kabeer (2006) in her seminal collection of work on *Inclusive Citizenship* argued for an alternative approach to citizenship framing and concluded that citizenship is given meaning by oppressed groups through a set of primary values including notions of justice, recognition, self-determination and solidarity. Kabeer argued that citizenship is, for many oppressed groups especially, about collectivism and the active engagement in wider political struggle, and that this practical reality is a central and critical dimension of citizenship claims-making. As Dagnino (ibid., p.22) pointed out in her chapter of this book, which is focused on a case study of Brazil, *"[struggle] constituted the essence of citizenship, even in the absence of formal rights".* It is exactly this participation in struggle which in support of, I ponder the strategic need of AT.

Kabeer's 'horizontal' view of citizenship, is important and relevant to the case of disability because it values the relationships between individuals, be they formal citizens or not, as 'at least as important' (Kabeer, 2005, p.23) as the relationship between state and individual, and is a shift away from the traditional liberal or neo-liberal understanding, which has disenfranchised many disabled people in the past.

In a context of changing political landscapes, the lived experience of citizenship for individual citizens is shaped by and shapes the physical landscape and intangible realities of families and communities; how people *'understand and negotiate rights and responsibilities, belonging and participation'* matters and defines their lived realities, often more than theoretical access to, or denial, legal status (Lister, 2007, p. 55). In particular, understanding citizenship from an embodied rather than a theoretical view (Kabeer, 2006, 2005) has particular relevance to disabled people, for whom the lived realities of embodiment are often very present (see section 2.2).

Everyday practices of citizenship are important in this view too, to the theoretical grounding of citizenship, however small they seem. As Lister (2007, p.55) emphasised *"we need to take stock of the imbalance between theoretical and empirical work".* The social, cultural and political activities that constitute the lived citizen realities of specific groups at '*multi-tiered'* levels of analysis - home, community, nation state, global – need to be understood within the spatial context, in order to understand *"how citizenship's* *inclusionary/exclusionary dynamics are experienced by both citizens and non-citizens"* (Lister, 2007, p.55). To this end we might view citizenship as an active process.

2.4.6 Citizenship as an active participatory practice

Lister gave a succinct argument as to why feminists have fought to demonstrate the role of active agency as giving meaning to the citizenship debate. She stated:

> *"partly, in order to avoid the danger of casting the excluded as passive victims of structural forces and other people's agency, a number of feminist citizenship theories have underlined the importance of political agency…(in citizenship terms)… This provides the link between conceptions of citizenship as an active participatory practice and as a set of rights which are the object of struggle"* (Lister, 2007, p. 52)

This is convincing as a narrative and rings true in conceptual intention, related to the understanding of human wellbeing above. However, it requires one to question whether the desired focus on empowering the oppressed group (in this case women, but equally disabled people) through giving meaning to political agency actually empirically influences or impacts their ability to overcome these same, very real, structural barriers, or indeed whether this is the most useful site to focus on – vis a vis legal rights for instance.

This question cuts to the very heart of this work: (how) does enabling and equipping poor disabled people with technology in order to enable them to claim their rights allow for better outcomes, according to the things they value and want to claim for? Most importantly what does the lack of AT mean, in terms of participation, in the types of vital but insurgent or informal action, for justice claims making. Let's look more at these sub-altern approaches.

2.4.6.1 The living politics of sub-altern political agency

This idea of creating new 'invented spaces' (Cornwall, 2002) where mobilisation can take place is popular in the progressive literature. The practical ways in which insurgency manifests against a repressive state have been documented by (Monson, 2015) in the case of South African squatter settlements of Jeffsville and Brazzaville, near Pretoria. She considered the case of perceived 'Xenophobic' violence against "foreigners" (those who were new to the settlement) who were often seen as "living for free" (ibid., p.51) by longstanding squatter residents, due in part to their failure to participate in (performative) actions of citizenship, such as marches, collective meetings etc. Monson (2015) used the "concepts of political identify, living politics and insurgent citizenship" to contextualise this violence by the existing squatted community against the "outsiders" (foreigners; p.40).

Her work is interesting particularly because she understands the 'mundane' realities of everyday living in the settlements, within the wider socio-political context. She locates the insurgency of the long -standing squatter communities (including that which is later turned violently upon the 'outsiders') as existing in collective opposition to the denial of formal citizenship rights by the state. Embedding this reality within an understanding of the SA concept of 'surplus persons' created by apartheid to expel Black South Africans from the cities, which she extends to the squatters, post-(formal) apartheid. This notion of exclusion, she argued,

> *"has animated collective mobilisation over the past two decades …and lives on in the squatters' unfinished transition to formal urban inclusion. …(magnifying)…the claims made …(and)…the techniques for protest and mobilisation which both activate and manufacture identities based on common suffering and civic labour" (ibid., p.53).*

The violence against 'outsiders', she suggested, should then be understood within the concept of *"the stratification of political identities and citizenship, which has produced particular localised historical struggles that in turn produce a logical structure to what is easily labelled as 'senseless' pathology of 'xenophobia'"* (ibid., p.53).

One might take from Monson's work, of particular relevance to this study, in conditions of informality, the following ideas. Firstly, it locates citizenship firmly within the physical space where communities are located - the place, and its historical, social, political and economic context matters. Secondly, it highlights the importance of the mundane, everyday, lived construction of insurgency within those wider contexts. Thirdly, it raises the question of who is 'in' and who is 'out' of even the informal notion of citizenship; the performative nature of 'inclusion' within this informal citizenship is vital to safety and belonging in her case study. Does what she found about the 'living for free' concept extend here if disabled people do not perform these rituals of inclusion? Finally, how does, drawing on (Chance, 2012a), the living politics of sub-altern political agency operate in the context of this study? Certainly, it is necessary to explore the informality aspect further.

2.4.6.2 'The Capacity to Aspire: Deep Democracy from below'

"Globalisation is producing new geographies of governmentality" argued (Appadurai et al., 2001, p. 22) and one expression of these new geographies can be seen in the relationship between 'cities and citizenship' as increasingly global cities operate - connected - within their own rules, norms and practices, potentially overtaking (some of) the roles of citizenship definition previously offered only by National States (Holston and Appadurai, 1998). The globalisation-driven emergence of mega cities and mass urbanisation in the Global South, has also generated "*high concentrations of wealth (tied to the growth of producer services) and even higher concentrations of poverty and disenfranchisement"* (ibid., p.25), and with it, high concentrations of poverty. It is within this context that *"movements among the urban poor…mobilise and mediate…they represent efforts to reconstitute citizenship in cities…(which constitute) 'deep democracy'"* (ibid.).

These movements of people operate within strong conditions of 'privatisation' of the state in various forms; what Appadurai termed '*redundancy'* when referring to the multiplicity of ways that traditional operation of the state contested from 'above' in 'positive' ways (e.g., the shared commitments to multilateral human rights agencies for instance), as well as from private capital and markets. Each aim to buy global activists and campaigners, such as disability NGOs, who work across borders necessarily to tackle global issues like climate change or inequality.

Appadurai (Arjun Appadurai, 2004) told the story of the Mumbai Alliance for Housing Rights in two specific informal communities fighting for housing rights and citizenship. The Alliance is formed of three organisations: the Society for the Protection of Area Resource Centres or SPARC (an NGO), Mahilia Milan (largely a women led-community savings programme), and National Slum Dwellers Federation. These organisations each have their own histories, make up, styles, methods and practices, which often widely differ. However, what is important about this story for the purposes of this research is specifically the way in which they operate - as one - seeking medium and long-term strategic solutions, rather than immediate outcomes and making their case through action as well as words. "*They commit to the partnership based on a shared ideology of risk, trust, negotiation and learning (and)…have agreed upon a radical approach to the politicisation of the urban poor that is fundamentally populist and anti-expert in strategy and flavour"* (ibid., p.29). Appadurai summarised:

"The Alliance (in Mumbai) has evoked a style of pro-poor activism that consciously departs from earlier models of social work, welfare and community organisation…instead of relying on a model of an outsider who teaches….(they are)… committed to methods of organisation, mobilisation, teaching and learning that build on what poor people themselves know and understand. The first principle of this approach is that no-one knows more about how to survive being poor than the poor themselves" (Appadurai, 2001, p. 29).

They also adopt a 'Politics without Parties' (to work with whoever is in power) and are pragmatic and grounded with a clear and performative, political vision for the future. With this vision they reject the constant push to respond to the immediate, in favour of a 'politics of patience', long term pro-poor planning, led by poor people themselves. Appadurai warned that it would be a mistake to view this as simply a politics of unity. Instead it is actually a very carefully and repeatedly negotiated 'politics of patience' constructed against the 'tyranny of emergency' (ibid.).

The strategies undertaken by the communities engaged in the Mumbai Alliance, and indeed now common in pro-poor movements connected to Slum/Shack Dwellers International (SDI) all over the world, have in common several tactics.

The first element that is relevant to draw out for a discussion on citizenship in this context is 'Federation'. By this Appadurai refers to respect for the fact that groups (even families) "*have a claim to political agency on their own and have chosen to combine their political and material power"* (ibid., p.32). The way that collectivism, negotiation and constant contestation is built into the process of constructing what it means to claim and create citizenship within the context of the Alliance, includes the principle of federating (as a verb) as prime. Formal association to the alliance and continued collective recruitment of others is a dynamic aspect of life. The power of the *federation*, for example to undertake community enumeration, to demonstrate, to make their case, is built upon their membership, which is self-built upon the agency of the facilities that choose to join it. This is key, because there is power in the decision to combine - there is something stirring of action in the commitment to be part of a bigger struggle. Reflecting on the often-isolated individuals who have impairments, which significant impact/ limit their lives, living in such communities, and who lack such opportunities or AT, a collective federated approach on the issues that matter very much to them might be a necessary factor for self-determination and citizenship. Certainly, exclusion from one's own potential for collective claims-making feels like a significant seam for further investigation as a thematic of citizenship generation.

The second factor is *savings*. Led in this case through the Mahila Milan women's group, micro savings are collectively encouraged (sometimes mandated) towards genuinely public goods (common facilities). This offers the potential to look to the future with 'hope' and helps to generate '*the Capacity to Aspire*' (ibid.), which is so necessary against the oppression of poverty which diminishes the circumstances in which people can "wish, want, need, plan and aspire” (ibid., p.x). Wishful thinking, or thoughtful wishing, is rarely individual, but part of a cultural system of ‘transgression and bawdiness’ (ibid.) through which the cultural voice and performance are used to translate the vision with and to the federation and beyond.

The third element which is of relevance particularly to this research investigation is the way the Alliance, and SDI internationally, use housing expos and toilet festivals to overcome stigma, reclaim dignity and demonstrate competence and innovation. This also has much to teach us in terms of the shame and stigma of living with an impairment and being a disabled person in many cultural contexts.

Tomlinson (2017) published a very helpful summary of the model of SDI and the Alliance work. The model encompasses community organisation (including through savings), prescient-setting (through small pilots), knowledge exchange (including community data capture), partnerships (to impact change), and policy advocacy. This is a model largely adopted in Freetown by organisations of the urban poor, as we shall see. The model, however, does not raise any identity specific elements in relation to disability, albeit specific in gender terms enough to recognise the value of women-led savings groups (ibid.).

2.4.6.3 Relational exclusion; redux

In the final part of this section, I want to return to the issue of the relational nature of exclusion, building on sections 2.4.2-2.4.3 the nature of citizenship has been further explored and consider its application to disability exclusion specifically. Walker and Ossul-Vermehren (2021) highlighted the work of Finkelstein (1980), who suggested that “disability is the outcome of an oppressive relationship between people with impairments and the rest of society” , cited in(Walker and Ossul-Vermehren, 2021, p. 168). This gives us a basis for investigating further, reflecting on the wider issues.

A relational approach to ‘durable poverty, inequality and power’ was put forward by (Mosse, 2010) who viewed persistent poverty as the consequence of historically developed economic and pollical relations, and emphasised that inequality results from social identity. Mosse’s thinking built on the manifesto of (Tilly, 1998) who examined the way in which differing social categorisations – race, class, gender, citizenship status in his case – present similar basic causes and inequalities, and found them aligned, despite basic categorical distinctions. The approach Mosse (2010) offered incorporates the type of multi-dimensional approach to power, that has been discussed earlier in this chapter, including the power to set agendas, which he argued sets the basis for both poverty and exclusion (ibid.). In short, relational poverty builds on Wood’s core point: “[Poor people are] unable to control future events because others have more control over them (Wood, 2003, p. 436) cited in Mosse, 2010). Mosse summarised the social relations of poverty as such:

> *‘..in many parts of the world (although I focus on India) persisting poverty can be viewed as a consequence of the exclusionary and expropriating aspects of long term processes of capitalist transformation”*(Mosse, 2010, p. 1156)

Mosse is considering cast and ethnicity as his primary identity case, and though there is much to separate these social identity groups in terms of construction and presentation of discrimination in context, the argument about the dominant influence of the current economic paradigm is hard to dispute. Mosse argued for the need to reconnect with the way in which social economic, political and cultural systems work (ibid.).

2.4.7 Conclusion – building a relational understanding into the framework

This section has provided insight into the current approaches to social development, citizenship and framing of poverty with relevance to disability. Particularly in the case of inclusive active citizenship claims making, there is a persuasive argument which talks to the bolder theme of participation as vital to liberation. However, these models are shown as an imperfect fit to disability claims making as they often focus on the local or community level. McRuer offered a potential rationale for this:

> *'It is largely at the level of the State that the 'disability category' is managed hence it is not perhaps surprising that level of protest and targeting of the disability movements have also targeted action at state level'* (McRuer, 2010).

What this means in practice is that while insurgent, inclusive, active or deep models of citizenship at community and city level have much to offer our understanding of disability inclusive citizenship, they do not as yet provide a wealth of examples of how these models have been used at community level to build the campaigns and freedoms of disabled people. This could be because of several further reasons. Firstly, because the current organisation of disability movements is usually at the national or international level, and usually organised around disability rights-claims making, not always taking good account of the poorest disabled people and their hierarchy of claims, which may – and often do foreground issues of urban poverty, as we shall see. Secondly, because the local level sub-altern governance is not funded, resources are sometimes minded to take best account of disability due to the hidden and stigmatised nature of identity. Thirdly, because though the potential value in combining struggles against poverty and disability subjugation holds great potential, examples of this struggles aligning in practice are limited and less well known of. That is to say, inclusive citizenship practices are not always inclusive of everyone, nonetheless, there is merit in the approach.

Taking forward this thinking to the framework in Chapter 3, if we borrow Kabeer's (2006) understanding that citizenship is given meaning by oppressed groups through solidarity, justice, recognition and self-determination, hold it loosely now perhaps turning to the literature on justice to offer some further clarity.

Summary of Key themes identified in this section with relevance to the framework

- We know that disability and poverty are mutually reinforcing (Banks et al., 2017; Groce and Kett, 2013), but further, poor people are poor, because of others (Wood, 2003).
- Poverty is relational (Mosse, 2010).
- Citizenship is given meaning by oppressed groups through solidarity (Kabeer, 2006).
- Traditional models of citizenship have subjugated disabled people to recipients rather than agents of justice, resulting in 'ablenationalism' (Snyder and Mitchell, 2010a).

- Inclusive citizenship (broadly understood) (Arjun Appadurai, 2004; Chance, 2012b; Cornwall, 2002; Holston and Appadurai, 1998; Kabeer, 2006; Lister, 2007) offers a strong theoretical model, but there is limited evidence regarding disability inclusion.
- Participation is an important means as well as end of development (Sen, 1999) and participation can be the mechanism to overthrow dominance (White, 1996).

2.5 Disability and Justice

2.5.1 Introduction

In this section of the literature review the relevant context on justice is summarised to highlight a set of concepts that evoke the approach to DJ this research will draw upon, which will come together in the framework presented in Chapter 3. Below, the seminal work of justice scholars, and the critiques offered from a disability perspective, are presented alongside a summary of the common use of radical ideas of DJ in practice today.

First, the primary problems of justice, who and what is covered, and what is meant by injustice, are considered in some depth from the perspective of the primary authors on disability and justice theory; this will highlight what disability studies has had to say about justice, and the issues of framing aligned to citizen status and the nation state. This section relates strongly to literature on citizenship presented in the previous section, as the relationship between disability, justice and citizenship is intentional, and is a theme which be returned to throughout this thesis.

This section also presents the radical model of DJ being recently used in practice by social movements in the disability space. This approach is built upon the perspective of intersectionality and the inter-connectedness of struggles for justice. The ten principles of DJ will lead us to our conclusions, before in the final section of this review (2.6) we will use these principles along with the evidence from the rest of this section to frame the premise for the investigation to come.

2.5.2 Dominant models of justice and disability critique

Justice is one of the most contested and debated terms in political science, and beyond it. The application of justice infiltrates day-to-day decision making within the legal system, government policymaking, and even in families and friendship groups as we ask: ‘what is fair?’ often without conceptualising this term. Frequently intensely theoretical, yet with immensely practical implications, justice debates can be characterised as being – very broadly – summarised as questions of: *who* is seen, who is entitled to their fair share and *how* that fair share is measured out; as Sen put it rather succinctly: ‘equality of what?’ (Sen, 1998). Fraser problematised: *‘There is a radical heterogeneity of justice discourse, which poses a major challenge to the idea of moral balance: what is the scale of justice on which these claims can be impartially weighed?”*(Fraser, 2008, p. 2).

We will return to Fraser’s (and Sen’s) positioning, which have useful practical implications and application in this study, but to begin with, in disability terms we need to go right back to the assumptions of the greatest theorists to ask, ‘*who counts’*?

As well as being the co-creator of the Capability Approach (Nussbaum, 2003), Nussbaum’s contribution to social development places her as a leading thinker in the implications for DJ. In a detailed and respectful deconstruction of Rawls’ (1971) version of the social contract, (Rawls, 1971) the ‘Frontiers of Justice’ (Nussbaum, 2006) lead us through a reconstruction of an alternative (capabilities) approach to justice, which has much to offer an analysis of justice for disabled people, and beyond. Her in-depth case studies reference disability,- alongside nationality and species membership (related to non-human animals), and are designed collectively to expose the flaws in Rawls’ assumptions. Nusbaum argued:

> *'Impairment and disability raise two distinct problems of social justice, both of them urgent. First, there is the issue of fair treatment of people with impairments, many of whom need atypical social arrangements…to live fully integrated and productive lives….(p99)…[Second] a just society, we might think, would also look at the other side of the problem, the burdens on people who provide for dependents."* (Nussbaum, 2006)

Some would critique the use of 'disability as a method' here - see (Kafer, 2013) for engaging critique of Haraway's 'Cyborg' (Haraway, 2013) as a method. Like the cyborg before it (ibid.) the abstractions of 'non-normal status' - often labelled as 'disabilities' (sic) - have been used here by Nussbaum to test many theoretical assumptions. However, Nussbaum's analysis is deep and complete, the approach used sensitive and thoughtful, and the implication well-considered for disabled people's lives. This critique is intended to challenge the very perception of *normality* (by Rawls) in service of a more disability-just understanding of justice. She is not the only intrigued academic who has been able to center disability while drawing out its wider theoretical implications, though she is in exceptionally limited company among core justice authors with a global profile of her standing. Mladenov sets out why this is pertinent:

> *"Over the last several decades, the social-political study of disability has revealed in something individual and biological (an 'impaired' body/mind) the key to something general and structural (social oppression)"* (Mladenov, 2020, p. 52).

It is necessary to understand the individual even at the most abstract level, to extrapolate to structural implementation. Further, it is possible to develop an informed perspective on disability, offering a broader implication of the findings. Yet, this is incredibly rare without caricaturing and reductionism. Nussbaum highlighted clearly that *"theories of social justice should be abstract"* (2006, p.1), by which she means they should be beyond and somewhat 'above' the day-to-day political conflicts of the time, even if such situations give rise to very real debates about such principles. In addition to being abstract, Nussbaum argued that *"theories of social justice must also be responsive to the world... [as is]…most theories of justice in the Western tradition, for example, have been culpably inattentive to women's demand for equality… since this requires….[among other things]… acknowledging that the family is a political institution, not part of the 'private sphere' immune from justice"* (ibid., p.1). This feminist critique is the starting point for a disability critique. To summarise a very complex argument, Nussbaum's critique on *contractarianism* formulated from a disability perspective is thus:

(1) *Exclusive justice*: the notion of 'rough equality' is predicated on the fact that those individuals - 'normals' - imagined (by Rawls) in the Original Position are supposed to cooperate on the basis of mutual benefit but without benevolence. Here, disabled people, who are not (all) able to 'contribute as much as they take' from society, and cannot (all) be perceived as mentally equally equipped to make such decisions, are excluded from the process of deciding the principles of social justice. Justice for disabled people – *'non-normals'* - is in effect delayed by Rawls to the legislative stage. Rendering participation in the *process* of establishing the basis of citizenship and justice though the social contract explicitly out of reach for all disabled people. *In short: justice is not for disabled people to participate in, but rather to receive.*

(2) The *'Normals'* classification also raises the issues of Primary Goods, which is also problematic as the basis on which justice is measured as this income proxy does take account of the needs of (many) disabled people - or all people throughout our lifetimes as we age and our needs change - including for the need for care, which we all will have as old people, and have as babies, be it paid or not. Rawls cannot accept 'care' as covered through a primary goods analogy in part because simplicity requires him to use only income and wealth to define the outcomes for 'rough equals seeking mutual advantage'(Rawls, 1971). He is also unable to include care because of his categorisation of 'normals' as people who do not require this. As Nussbaum summarised: *"without extensive modification of the political conception of the person, Rawls cannot imagine primary goods as including the needs for care that characterise citizens with … impairments, whether lifelong or temporary"* (Nussbaum, 2006, p. 141). *In short: the assumptions made about resources needed do not take account of the needs of disabled people.*

(3) The *Difference Principe*: Nusbaum stated: *"many of the problems of Rawls's theory faces in the area of disability derive from his interest in the theoretical simplicity as it shapes his account of the toll of primary goods in indexing relative social positions"* (2014, p.146). To accept this approach we "*require a major overhaul of the (Rawls' social contract) theory, particularly the theory of economic justice" [as] "…issues of Impairment and disability prove very revealing for the entire structure of Rawls' contract doctrine and, more generally, for the project of basing principles of justice on reciprocity between rough equality [of participants (in capacity)] who are imagined as joining together to reap a mutual benefit"* (ibid., p.145). This is problematic because to overhaul the Difference Principle, held tight by Rawls to enable the simple logic of his theory, would unravel his approach. Yet for those that are different – everyone? – this is too simplistic as to represent reality and therefore is it a useful model for all (Nussbaums's extrapolation), or certainly for disabled people. *In short: the theoretical simplicity of Rawls' approach excludes difference, ergo diversity ergo disability.*

If we accept these propositions presented by Nussbaum, we must look for an alternative model of justice. Nussbaum's own theory offers value to people's opportunity to live good lives *"to be primary, and the account of political justification to be posterior, to an account of what makes lives in accordance with human dignity possible"* (ibid., p.154) which is – I believe - a good point of principle to start with.

More recently, offering a *'Capability Theory of Disability Justice'* (Pineda, 2020) presented the idea of "distribution of justice as a fundamental, participatory, and deliberative process wherein social values are developed and implemented by the people most affected" (ibid., p.25). This draws out the principles of agency and autonomy found in Sen's own ideas of justice (Sen, 2010) which impart within the principles of justice - the centrality of public reasoning - for those affected by decisions of justice to participate in the very same. The removal of injustice, rather than the pursuit of perfect justice (even If there was agreement on this) becomes the organising principle here. Diagnosis of injustice, as a starting point for a critical discussion about what justice is, naturally involves those affected, and this is directly relevant to this work (Sen, 2010). Sen's exercise of proactive pluralism - "what matters most is the examination of what reasoning would demand in the pursuit of justice – allowing for the possibility that there may exist several different reasonable positions" (Sen, 2010, p. xix) – becomes core to the idea that AT is necessary to enable justice, through the participation in the very same. Without AT, neither deliberation, nor pursuit of the removal of injustice in one's own interests is possible.

We now move on to discuss how Disability Studies considers justice.

2.5.3 Disability studies and justice

Another way to frame the problem of defining DJ is to approach it from a different angle, and to highlight that disability studies has '*emerged!'* (Garland-Thomson, 2013) as a substantive and vibrant academic field (Davis, 2016) (Garland-Thomson, 2013) with two key mechanisms of exploration; disability as an analytical field uniquely describing the experience of one billion people, or, as evidence that people are on a continuum of capability and function (related to IFC for instance). Neither the relationship between the two, nor the way in which people identify, are sufficiently understood (Grue, 2016). To add to Grue's analysis perhaps the qualification, that Disability Studies' core thematics are also usually focused within a given political, economic and social set of assumptions, infrequently contextualised (in the context of the Global South urban poverty, for instance), nor understood in its intersectional complexity. These are all hard tasks for an interdisciplinary field, however it has 'emerged'.

Individual and collective justice

The notion of legal 'rights' has been equally hard won, through the CRPD among other things, and hard fought for at national levels, offering a focus of writing, organising, polemic and struggle for many decades. Many scholars and activists would argue, with some considerable evidence presented in this thesis, that legal rights are a fundamentally necessary factor in disability emancipation. However, the focus on individual Human Rights, as the CRPD does, negates the collective, by definition (Shakespeare, 2014). The pretence that issues of justice are experienced by disabled people in silos, and that they can be solved in isolation too, is perhaps the greatest trickery of the modern capitalist political consensus. We looked in earlier sections at the ways in which neo-liberal approaches are informing the distribution of goods and access to welfare for individuals based on a restriction of the disability category (Mladenov, 2015a, 2015b), rather than viewing the need for support as a collective need as (Piepzna-Samarasinha, 2018) would advocate.

There is some evidence that this neo-liberal consensus is being challenged, with people searching for answers in arguably the wrong places (populist governments); such that *while the old is dying the new has not yet been born* (Fraser, 2019)! Yet, the actors who benefit from seeing justice claims as separate concerns (gender, disability, climate) are those who are benefiting from negative externalities of production, or the enclosure and division of labour (Fraser, 2014). Those same people, who are the top 1% reaping the benefits from this alienation, are attempting, either explicitly or implicitly, to avoid the dis-benefit of those experiencing injustice, coming together. The collectivisation of the siloed interest groups into a collective whole, capable of overturning the political, economic, environmental and social systems which oppress them, is clearly not in the interest of those benefiting from the status quo. Doubling back to Sen's point, making space for pluralistic agency becomes what Trotsky would call a transitional demand (Trotsky, 1938).

2.5.4 Marxism and the ‘transitional demands’ of justice

I set out quite clearly in the disability section of this review (2.2.5), that the Social Model of Disability has alignment to the materialist dialectic and Marxist thought. I also discussed the various interactions between the political socio-economic paradigm we live in, neo-liberalism, and access to AT (in section 2.4.4), and considered the role of the neo-liberal approach to citizenship (in 2.4.5). All of these sections (2.2-2.4) concluded that in some way an analysis of the capitalist approach to the distribution of resources, is relevant to this study. Therefore, it is also relevant to consider the ideas which challenge this approach critically. Not least because there are some theoretical tools that Marxism uses, which can aid the understanding of justice claims making, most notably I want to reflect on the idea of transitional demands.

Traditional socialist approaches often take poor account of disability (Bengtsson, 2016) and a direct read of Marx looking for disability does not return much data (Bengtsson, 2017). However, the idea that remains directly relevant is the understanding Marx presents of our economic system (now: neo-liberal, advanced capitalism), which he believed contains within it, the seeds of its own destruction. This is due to the instability of the capitalist proposition which requires the exploitation of the many by the few, held up by a series of ‘background conditions’ (Marx and Engels, 1948). These ‘background conditions’ include the means for labour reproduction, political stability and public governance, financial infrastructures set up to enable the accumulation of capital by the owners of the means of production, and non-human nature which reproduces raw materials for use in the production process. Traditionally Marxists understand these Background Conditions as merely inputs to the centrally important *economic* system of neoliberalism (Fraser, 2022). In short, the alienation of the working class (and other subjugated peoples) is brought about through the exploitation of wage labour where the profits of this labour are extracted and retained by the ruling class.

Fraser, however, built on this theory by going further. She set out , with unique clarity in the modern context, what this means for the women behind Marx’s hidden abode (Fraser, 2017). She suggested that in the modern day, women face huge alienation through the social reproduction of labour since women (almost always) engage in the unpaid work of birthing, caring for, refuelling, and ‘resting’ labourers ready for work in the production of value to be expropriated by the 1% who own it. This dimension of her reading of Marxism gives rise to her analysis of *recognition* as well as *redistribution* as a significant organising principle for analysis. As we shall come on to see, this shapes her view of justice which we shall borrow and adapt.

To take the point further, in recent work Fraser considered the exploitation of the environment also through the mechanisms of capitalism, where the costs of environmental damage are externalised outside of the production process to the benefit of those who own the major means of production and accumulation of wealth (Fraser, 2021a). Thus, to her, the working class, women, and the environment are all alienated through the system.

She also argued that the political system of rules and regulations – essentially our understanding of democracy itself - are necessary to hold up the neo-liberal economy and avoid it collapsing into its own destruction (as Marx and Engels predicted), and that this system of democracy is critically broken. With confidence in the political hegemony - as understood in the consensus world order since WW2 – both fading and failing, borrowing from Gramsci, she summarised *"the old is dying but the new cannot yet be born"* (Fraser, 2019).

Fraser suggested that these series of 'crises of capitalism' (Fraser, 2021b) are leading to the rise of untethered right-populist leaders (Trump, Modi, Bolsonaro, Johnson) who are rising on a tide of cult personality sponsored by tech conglomerates and fake news, filling the gap that this disintegration of the neo-liberal hegemony has left (Fraser, 2019).

In her most recent book (Fraser, 2022) built up to a wider definitional understanding of Expansive Capitalism as more than an autonomous economic system receiving inputs from the Background Conditions (Marx's base-supersystem model). Rather, she posited that the connection between the Background Conditions and the economic system are dynamic and relational. That is to say, it is not a one-way street. Impact in the background can cause a crisis in the economic system (see COVID-19, for instance) as well as the other way around (Fraser, 2021b). This matters for disability justice because it changes the *what* and the *how* of justice claims making.

Fraser suggested this dynamic relationship has added up to a series of crises in several sectors. The (still unresolved) 2007/8 financial crisis, the waning support for the post war political hegemony in the form of a political crisis making way for right (and sometimes left) wing populists, a crisis in social reproduction of labour caused by ever-expanding costs of child/ elder care (falling on women), disinvestment in welfare, all are exacerbated by COVID-19. Additionally, the climate crisis – perhaps the most significant of all – which is evidence of Capitalism eating itself (ibid.). This, she suggested might sum to an **epochal crisis**, the sort of which we have not seen before, and may lead to a change in the current neo-liberal capitalist ordering of society resulting in a variety of positive (broad coalition for eco-socialist democracy), and not so positive (ungoverned warmongering and/ or regressive feudalistic) outcomes. She made no predictions but committed to organise for the former by, in the beginning, mapping a route to broad coalition which identity and class-based struggles for redistribution, recognition or representation can place themselves within and as a part of it.

Forgive my apparent segue, for it raises a vital and interesting question for this study, which is about how this evolving justice thinking and approach can offer a roadmap for DJ, because when faced with the need for a choreography of interventions to support urban poor disabled people, these first principle questions become the most important to answer: essentially: what's the goal? who are we 'for'? and in what order should we tackle the priorities?

2.5.5 Disability Justice as 'boundary struggle' in a global justice movement?

What is significant and new about the type of justice thinking in Fraser's most recent work, is that she has then charted the crisis in the political system (albeit from a very Global North vantage point) down to right/ left populism and progressive/reactionary neo-liberalism, recognising that distribution (or wealth) and recognition (or identity) are intersecting axes providing interesting results. As her expanded concept of Expansive Capitalism allows the Background Conditions to feature as dynamic in the model, she also **expanded the distinction of 'class struggle' as the process of consciousness-raising against core demands beyond the traditional understanding**. She argued *"class struggle can sometimes take the* *form of boundary struggles"* beyond those for traditional redistribution, these struggles relate to *"the grammar of how life should be organised"* (Fraser, 2021b). This raises the question: who is involved in the struggle and what are the demands?

At this point it is helpful to identify the definition of a transitional demand, which are those strategic and vital demands that can bridge the simple claims necessary today (Marx's minimum programme), toward transformational change (Marx's maximum programme) – they are necessary factors in the struggle for a better world, as well as being fundamentally important in and of themselves. The following paragraph summarises this principle:

> *"It is necessary …to find the bridge …this bridge should include a system of transitional demands, stemming from today's conditions and from today's consciousness:… [they bridge] …the minimum program which limited itself to reforms within the framework of bourgeois society, and the maximum program which promised substitution of socialism for capitalism in the indefinite future'(Trotsky, 1938, p. 114) .*

Links can be made here to Fraser's (2005) idea of affirmative and transformative solutions. I would like to hold this idea in mind, and the empirical work to come will borrow this idea of transitional demands and will begin to think about what relationship AT might have with such a transformation. Some of the pertinent themes relate the understanding of where the legitimate boundaries of markets should be? Is AT one of those spaces? And what are the options for disability justice in this context following her analysis?

We will return to a simplified version of Frasers' argument below and use it to inform the framing for this study, but I want to go deeper into the Global South context.

2.5.6 Justice in the Global South

If access to justice is a right based on human rights obligations and is a 'backstop' against inequality for persons living in poverty, it means people are capable of claiming their rights (Sepulveda Carmona and Donald, 2014). Access to justice can however be uneven, within and between countries; at its most basic level "*a well-functioning justice system offers a mechanism to solve disputes without violence and weapons…in developing countries the barriers of access to justice are most tangible…and have the biggest impact on the poorest people"* (ibid., p.3*).* However, as discussed above, recourse to justice can be incredibly difficult for an individual living in poverty, where often community based justice systems, however informal, are the only justice poor women and men can access:

> *"Although discriminatory patterns manifest themselves differently across regions and within countries, in every country in the world the poorest and most marginalized segments of society - commonly women and girls, ethnic minorities, indigenous peoples, undocumented migrants or those living in rural areas - continue to be excluded from accessing justice on an equal footing with the most privileged groups [...] of the population. Even in the most developed countries, legal disempowerment is rife and persons living in poverty do not have full de jure or de facto access to justice. This means that globally, persons living in poverty are often prevented from*

> *claiming, enforcing and contesting violations of their rights"* (Sepulveda Carmona and Donald, 2014, p. 7).

The equation of national boundaries with the boundaries of rights claiming, is one common challenge inclusive citizenship scholars have levelled (as set out in section 2.4) but the relationship between rights, citizenship and justice can be explored further.

2.5.7 The relationship between 'rights', citizenship and justice

Some view this relationship very clearly: "Legally enforceable rights and duties underpin a democratic society, and access to justice is essential in order to make these rights and duties real" (Sommerlad, 2004, p. 345). However, others have sought to draw a distinction between Social Justice and citizenship focused on individuals as members of a societal community (Bernts et al., 1992). Feminists have long argued that "democratizing the sexual and emotional spheres of life, together with formal politics and economics, and promoting a horizontal rather than hierarchical notion of relations between men and women will "democratize democracy" (Giddens, 2003, p.76) and extend and enrich the idea of citizenship" (Maier and Alvarez, 2010).

In fact, assuming tessellation between notions of rights, citizenship and justice becomes an important assumption when seeking to understand the relationship between disability and justice, as well as disability and citizenship, because , we have seen, while legal rights may be a necessary factor in justice, they have unjust recourse and coverage.

Furthermore, often scholars have given equivalence to the idea of the bounded nation state as the mechanism for administrating justice and the orchestration of true citizenship. This has historically been a practical reality prior to globalisation and mass movement of people around the globe (often caused by the climate crisis). However, in the modern age of international corporation a simple glance at the Pandemic Crisis indicates these major global issues paying little or no heed to socio-political borders and administrative boundaries. The 'Westphalian problem' is Fraser's (2008) moniker that refers to exactly this, and as the bounds of nation states are evaded and the "…dubious …view of territoriality as the sole basis for assigning obligations of justice, given patently trans-territorial problems such as global warming… prompts many to think in terms of…expand(ing) the bounds of justice to include everyone potentially affected" (p.5). She is not alone in her critique, others have contended that the insurgent citizenship (Holston and Appadurai, 1998) of citizens and non-citizens alike is bounded more practically by the relationship, whether formal or undocumented, to the City than the nation at all.

The hegemony of understanding justice as framed by the national state, and hence rights and justice as only applicable to 'fellow citizens', has been dominant for decades. However, today's claims for feminist, religious or communal justice transform justice discourse to a 'radical heterogeneity' which contradicts this approach (Fraser, 2008, p. 2). Post-Westphalian accounts of the 'who' of justice must take seriously the political nature of this framing. Instead of relying on this historical assumption, Fraser offered a theory of justice which responds to this, in three parts, as we shall see below. I now return to Fraser's work to set the tone for a deeper discussion of DJ.

2.5.8 Parity of Participation

In *Reframing Justice in a Globalising World* (Fraser, 2005) set out a new critical theory of justice aimed at clarifying the 'who' of justice as well as the 'what' and the 'where'. She subsequently evolved her thinking, with a resulting theory of justice in terms of a tripartite approach to Participation Parity (Fraser, 2008), which she presented by expanding her earlier framework. *Parity of Participation* constitutes of (economic) *redistribution*, (cultural) *recognition* and (political) *representation*. (Fraser, 2000)summarised her argument as the struggle for recognition of social identities - race, gender - have been growing pace in recent decades ('70s, '80s), but this 'politics of recognition' became detached from the struggles for economic redistribution (on the decline, post communism). These 'claims of difference' became the dominant force in many global conflicts distorting the original intention of many of these struggles (emancipation of the group with an oppressed identity) in favour or valorising or justifying capitalistic approaches through tokenism, or being misappropriated for nationalistic power struggles. The *reification* that identity politics dictates, functions as misrecognition, she argued, and I add also as invisibility. Further, this crowding out of debate on redistribution functions as *displacement* and enables the continued maldistribution of wealth and assets capitalism requires. For disability, the case follows; though at a very different pace, especially in the case of those in many countries in the Global South where the struggle to remove negative association of disability is real and invisibility, and lack of collective action are pressing second and third concerns. And so, Fraser argued: "What is needed, rather, is an alternative politics of recognition, a *non-identitarian* politics that can remedy misrecognition without encouraging displacement and reification" (Fraser, 2000, p. 120).

In her recent work, Fraser went much further, bringing in environmental justice (Fraser, 2021a). She argued coherently that while the post Keynesian consensus has been popularly discredited (the old has failed), a new model of just governance is yet to take hold and replace it (the new has not yet begun). This gap she suggested, is being filled with populist struggles, despots, alt right causes and personality driven leaders – of which identity is often harnessed as a central organising principle. We need, she argued, a new grammar of political language through which to address this (Fraser, 2019).

Fraser's framing is so helpful because it offers a coherent, tangible, practical theory of justice which recognises that justice is political, economic and cultural in nature. It does not see the frame as nation state-based, but rather accepts that in a globalising world injustice and the conditions for justice are global too. Perhaps what is most important about Fraser's work for this study, is that she refuted the idea that a choice must be made between the 'politics of recognition' at the expense of the 'politics of redistribution'. This is a charge often levelled by a part of the socialist left at identity-aligned groups such as those supporting disability, sexuality or gender, in the face of the main concern (overthrowing capitalism). Fraser's ability to present both, alongside a centring of representation too, has much to offer to a disability study focused on conditions of poverty and informality.

Our recent paper which summarised the early findings of this research explained:

> *"Borrowing from Fraser one might summarize that issues of misrecognition (of identity), maldistribution (of access to resources, including AT), and the resulting mis-representation (or lack of representation in key citizenship activities) were incredibly*

> *present for slum dwellers with disabilities. This resulted in a rather literal 'dis-parity of participation' for slum dwellers with disabilities, functioning as an operational model of injustice. The interventions necessary to dismantle this construction and recreate a disability justice model relevant for this context, deserves much further analysis" (Austin et al., 2021a, p. 23)*.

Additionally, it is just this further analysis this thesis hopes to offer for the issues of participation parity are not a clear cut as the summary might belie. In fact, much more consideration is needed. For instance, the following themes emerge from the data:

- The potential for *reification of innovation*, as a pretence at overcoming the human and non-AT related support required.
- The implications of the consequences of neoliberal status quo like low wages and poor contractual terms
- Who is involved in the provision of AT?
- AT for what? AT which enables poor disabled people to enter the employment market is not the only viable use, and the complexity must be explored.
- A*bleism & able-nationalism* in the production and design of AT; who makes it, how are users involved and is it fit for purpose in context?
- Issues of *climate change* exacerbated by cheap, low quality, imports are considered the 'solutions' to local AT need, where local repair solutions do not exist for such products, too.

These points will be explored in the following sections.

2.5.9 Justice in the neo-liberal reality

I return now to Fraser's ideas in the face of neo-liberal dominance, discussed above. Table 2 below, is an edit and adaption of Fraser's most recent work (Fraser, 2022), which summarised the role of political paradigms via their leaders, in supporting the elements of the Fraser's Justice analysis; with implications added to highlight the type of justice proposed, as relevant for DJ. The table below is adapted from her work on feminisms, where she deconstructed the notions of feminism proposed by, for instance 'lean in' (Sandberg, 2015) style proponents and those who seek more transformational change. Where Fraser talks about the politico-economic paradigm, she is inferring the difference between acceptance of and rejection of 'the status quo' – neo-liberalism.

In the final column I note the implications this has, or may have, for DJ by taking licence to assume for the basis of this study that Fraser's model can be extrapolated to overarch all identity and recognition categories. **Following Fraser's thinking to the logical conclusion then, there are two options for disability justice for poor disabled people. Option 1 is 'lean in' style corporate diversity and disability inclusion, and option 2, is a broad movement for progress which has DJ at its heart.**

Table 2: Politico-economic paradigms and implications for disability justice

Politico-economic paradigm	Example Leaders / Administrations	Distribution / Recognition	Implications for disability justice for poor disabled people.
Progressive Neo-liberalism	Clinton, B. Blair, A, Obama, B., Rodham-Clinton, H. (Candidacy)	No redistribution of wealth (active support for neo-liberal hegemony); 'Progressive' approach to recognition - which functions to 'de-toxify' the elitist approach to politico-economic management.	'Lean-in' style 'corporate diversity' disability inclusion work is sanctioned / encouraged - similar to 'meritocracy' of LGBTQ, or Women or BAME leaders, Disability is promoted in key sectors (see for e.g,. Valuable 500 (Valuable 500, 2022)). Mainstream interventions which don't challenge the root of injustice by promote disability inclusion for those already in the managerial/professional class within the existing system.
Reactionary Neo-liberalism	Trump, D. (presidency) Bolsenao, J., Modi, N.	No redistribution of wealth (neo-liberal hegemony); Reactionary approach to recognition	Withdrawal of / no support for disability inclusion or active stigmatisation of poverty experienced by disabled people. Disability identity may be attached/ weaponised and stigma encouraged.
Reactionary Populism	Trump, D. (Candidacy) Vote Leave (Brexit, UK)	Articulation of the case for redistribution of wealth (question: is implemented in practice?) **No support for recognition**, or a reactionary and (at worse) racist/ xenophobic response to recognition.	Withdrawal of / no support for disability inclusion or active stigmatisation of poverty experienced by disabled people. Disability identity may be attached/ weaponised and stigma encouraged.
Progressive Populism	Corbyn, j., Podemos, Bernie Sanders Candidacy	Articulation of the case for redistribution of wealth AND	Disability movements aimed at raising wide popular support (for instance #Wethe15? (*WeThe15*, 2021, p. 15)) form part of coalition for a global, progressive, left-wing politics which is both respectful of

		Articulation of **support for recognition** and diversity	identity and anti-capitalist/ eco-socialist.

These are just some of the complexities that shall be explored further. Yet, what Fraser's justice frame allows for is simplicity among the complexity – through her recognition, redistribution, representation approach - while retaining an acceptance of the interconnected nature of reality where disability justice is but one aspect in an overarching practice of justice for all. Now we move on to explore the current work on Disability Justice coming out of radical social movements led by disabled people.

2.5.10 Disability Justice as a radical practice

Disability Justice has increasingly been used in recent times by activists, to refer to intersectional claims for justice which have been brought to the fore by disabled, queer, Black and Brown, women and trans people. Most notably, this is evidenced through the work of the Disability Justice Collective, a coalition of US based activists who grew in a large part out of Sins Invalid. Sins Invalid is "*a performance project on disability and sexuality that incubates and celebrates artists with disabilities, centralising artists of colour and queer and gender-variant artists and communities who have been historically marginalised from social discourse*" ("Sins Invalid," n.d.) based in San Francisco.

Their Disability justice Primer (Invalid, 2017) sets out what they believe to be the fundamental principles of DJ, articulating why a single issue disability movement, with its locus on commonly understood 'rights', must relocate toward a intersectional force for change aligning the struggles of those fighting ableism with those struggling against homophobia, racism and transphobia, or those fighting oppression on the basis of migration or health status (Invalid, 2017). To be clear, their call is not against rights, but a push to move beyond a legalistically driven rights-based framework to an intersectional framework for interconnected justice for all. Their principles begin with a reflection that:

> *"There is no such thing as a single-issue struggle because we do not live single-issue lives."*(Lorde, 1982)

Their ten principles of DJ are reproduced in Figure 5, below.

10 PRINCIPLES OF DISABILITY JUSTICE

1 **INTERSECTIONALITY** *"We do not live single issue lives" --Audre Lorde*
Ableism, coupled with white supremacy, supported by capitalism, underscored by heteropatriarchy, has rendered the vast majority of the world "invalid."

2 **LEADERSHIP OF THOSE MOST IMPACTED**
"We are led by those who most know these systems." --Aurora Levins Morales

3 **ANTI-CAPITALIST POLITIC**
In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.

4 **COMMITMENT TO CROSS-MOVEMENT ORGANIZING**
Shifting how social justice movements understand disability and contextualize ableism, disability justice lends itself to politics of alliance.

5 **RECOGNIZING WHOLENESS**
People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.

6 **SUSTAINABILITY**
We pace ourselves, individually and collectively, to be sustained long term. Our embodied experiences guide us toward ongoing justice and liberation.

7 **COMMITMENT TO CROSS-DISABILITY SOLIDARITY**
We honor the insights and participation of all of our community members, knowing that isolation undermines collective liberation.

8 **INTERDEPENDENCE** We meet each others' needs as we build toward liberation, knowing that state solutions inevitably extend into further control over our lives.

9 **COLLECTIVE ACCESS** As brown, black and queer-bodied disabled people we bring flexibility and creative nuance that go beyond able-bodied/minded normativity, to be in community with each other.

10 **COLLECTIVE LIBERATION** No body or mind can be left behind -- only moving together can we accomplish the revolution we require.

SINS INVALID 2015 www.sinsinvalid.org

Figure 5: The Ten Principles of Disability Justice as imagined by Sins Invalid (Berne et al., 2018)

As noted by (Barton, 2021), Berne et al.'s (2018)Ten Principles of DJ offer opportunities to build the movement in new areas embracing DJ in new contexts. This approach also allows us to move beyond a 'level playing field' (Shakespeare, 2014) approach to equality, toward real justice.

Like previous drives on gender or sexuality, this approach is built on the assumption that with the right conditions, and the removal of cursory barriers, we assume we can all participate equally (or at least equitably) in the same held fast notion of what society, or economy are or should be.

As Shakespeare put it:

> *"If people can get access to health and rehabilitation, rely on accessible transport from accessible homes to accessible schools or workplaces, and receive what human*

> *rights lawyers describe as "reasonable accommodation" in education and employment, then they can learn and earn and live a 'normal' life….is that enough?…some people will never be able to compete in a liberal free market order…To address the limitation of the equality-based model and ensure a good quality of life for all, we must move away from liberal individualism -which links its notions of equality to idea of work…we need to change social systems and social values not simply try to integrate people with disabilities*. *(Shakespeare, 2014, n.p.)*

As highlighted in Piepzna-Samarashinha's reading of the Sins Invalid work *"this Disability Justice, an honouring of the long-standing legacies of resilience and resistance which are the inheritance of all of us whose bodies and mind will not conform. Disability Justice is not yet a board-based popular movement. Disability Justice is a vision and practice of yet-to-be, a map that we can create with our ancestors and our great-grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which everybody and mind is known and beautiful"* (Piepzna-Samarasinha, 2018, p. 29).

Perhaps another way to put this, after (Fraser, 2000) would be where everyone is recognised and feel they can belong. I will return directly to this combination of thought after a final segue into the emerging work on AT and DJ, and one example of DJ in practice.

2.5.11 AT in the DJ literature

In very recent times, there has begun to be more use of the idea of DJ in the work around AT. It has not found its way into the mainstream yet but has much to offer. As Sum et al. (2022) set out in their recent work for the HCI conference the focus on single axis oppression (rather than DJ which recognises intersectionality) has resulted in the reality that "HCI and assistive technology research may not always attend to the complex lived experiences of disabled people" (Sum et al., 2022, p. 1).

Further, some scholars have begun to think about justice models as a mechanism to consider access to AT, for instance (Stramondo, 2020) set out an approach to justice as a mechanism to comprehend AT access. Rejecting both the broader approach to healthcare access and the CA as neither being able to overcome the problem of *contrition* (where theory does not justify enough of the AT that people need), or the problem of *overextension*, where the theory cannot identify an upper limit of AT that people have a right to, Stramondo made the case for "*AT as part of due compensation for the harms they [sic] experience from being disadvantaged by society's dominant cooperative scheme and the violation of their right to equality of opportunity that such disadvantage entails"* (Stramondo, 2020, p. 247). This is interesting although the perspective is such that the author defines AT as any technology that confers disability group identity on the user (ibid.). This is slightly challenging of the definition I have adopted so far, and for me raises issues beyond the scope of this section regarding stigma, the agency of the technology and its use in practice; the paper has a medical emphasis, and tends to over-rely on the idea that the technology is solely there to 'fix' the disability issue. While it is an interesting approach to think about justice as an arbiter of access, I think it is unlikely that this will move beyond the principles to the specifics Stramondo (ibid.) imagined.

Finally an emerging movement of critical tech theory is also emerging with (Rauchberg, 2022) imagining 'neuroqueer technoscience' as an extension of 'crip technoscience', amplifying new styles of relationality and self-expression using HCI. I referred earlier in the AT section (2.3) to the need to think sceptically about technological innovation and I think this applies here too. Nonetheless the idea of a reclamation of tech innovation from a queer and intersectional perspective feels valid.

These are new and emerging fields, with limited context, to which I hope this work contributes. Before I move into the conclusion, I want to take one example from practice of applying DJ to a live project, which I worked on before GDI Hub. This research was done in 2020 and is relevant because it has helped to shape AT2030.

2.5.12 Disability Justice in Practice; a London 2012 case study

The London 2012 Paralympic Games was the most successful ever in terms of ticket sales, broadcast, number of athletes, numbers of disabled volunteers and staff, and the first time the Olympic and Paralympic Games were integrated together fully with one organising committee for both, the disability aspect led by the Director of Paralympic Integration (and Paralympic gold medal winner Lord Chris Holmes). It brought disability sport, ergo, disability, to millions of people for the first time through TV coverage and Paralympians became global heroes. London 2012 also delivered the most accessible Olympic Games ever, with both events held on a purpose-built accessible site in East London with unique interventions like a Built Environment Access Panel of disabled people who had the power of veto on all plans (Austin et al., 2021b). This paper (ibid.) published alongside the Tokyo 2020 Paralympic Games (held a year late in 2021), sought to retrospectively frame the disability inclusion approach of London 2012 in order that it might be tested, adapted and used to frame other projects, including, notable, AT2030 and the launch of the world's biggest disability movement - #WeThe15 (*WeThe15*, 2021, p. 15). The resulting framework is set out below in Figure 6.

The reason for including this London 2012 case study in this thesis is threefold:

(i) It illuminates the vast need to move disability rights from the invisible to the visible sphere. The choreography of this is significant; should this be done with the intention to maintain the balance between recognition and redistribution, or should we allow for a bit of acceleration on the recognition side before coming back into alignment with redistribution? It raises a critical point for Fraser's theory – how, in what ways, and with which limits do unrecognised groups catch up?

(ii) The research raises a further question - when does representation become the fundamental organising principle according to the evidence? For London 2012, many expected the commitments made in the Bid Book submitted by the City (in 2005) to be the starting point for disability inclusion organisations. However, that was not found to be the case. It was the penetration of community collective wisdom, through infiltrating the ranks of key agencies as staff, enabling the co-option of ideas, the influence of politicians, in short, community leadership – that set the tone and the strategy for inclusion on London 2012. It highlighted that representation was first, last and middle of the success.

(iii) Finally, the 12-step disability inclusion model, is one of the few attempts to map empirically how disability inclusion was delivered in a major global programme.

The intention is to inform others. An attempt to do just that, vis-à-vis the AT2030 programme is presented in Chapter 8.

Figure 6: Disability innovation framework, taken from Austin et al., 2021.

The implications of the inclusion of this case study for the investigation to follow, is to offer a real-world example of the complexity to the choreography and alignment between recognition and redistribution, and to underline the central importance of representation as 'first principle' of any intervention intended to accelerate justice for disabled people. Additionally, it can be seen as a tool for analysis of the global AT space.

2.5.13 Conclusion

This section has shown that the traditional notions of justice do not always take good account of the 'who' of justice if our interest is in the inclusiveness of disabled people. I also argued that the framing of justice belies a deep debate about citizenship and recourse to rights, which are often forsaken to poor or excluded communities. These formal and academic debates are not often salient, with the issues of those struggling against ableism and urban poverty daily – where the necessity to seek justice engagement in informal arrangements of community governance which are more immediately impactful exists. The section made space for a dive into the role of the socio-economic political system, in both reinforcing the context within which these debates arise, and in setting the tone for what is possible. We examined the idea of what type of justice is possible and what the demands of a justice movement in the neo-liberal context could be. Frasers' Parity of Participation framework allows us to move forward carrying both complexity and simplicity. Through the intersectionality of the radical construction of DJ, the social movement Sins Invalid is careful to reflect on a set of principles for interconnected justice for all. I borrow both important constructions now to frame the investigation in the next chapter.

Summary of Key themes identified in this section with relevance to the framework

- Disability is not well account for in traditional justice models which see disabled people as recipients, rather than agents of justice decision making;
- Justice in the form of Representation, Redistribution and Recognition related to the struggles of disability justice (Fraser, 2000);
- Disability Justice viewed as a Boundary Struggle in the global justice Movement (Fraser, 2022);
- Context of neo-liberal advance capitalism and the role of Transitional Demands as a bridge to transformative change (Trotsky, 1938);
- Justice as intersectional and interdependent, requiring of solidarity (Berne et al., 2018).

3 Constructing a framework for analysis

3.1.1 Introduction

The literature review in Chapter 2 naturally reveals complexity covering four very contested dimensions. However, to set the tone and scope for the investigation to come, this chapter seeks to clarify this vast body of work, through building a framework which can support answering the research questions. To begin, I will demonstrate the concepts that have been adopted as most useful, from the four dimensions. These then guide the design of the framework itself in the second part of this short chapter.

3.1.2 Framing the analysis: key concepts adopted from the literature review

At the end of each section in Chapter 2, I set out the core concepts which I had analysed and found relevant to the investigation. The following diagram sets these out again, against the domains I reviewed in the literature.

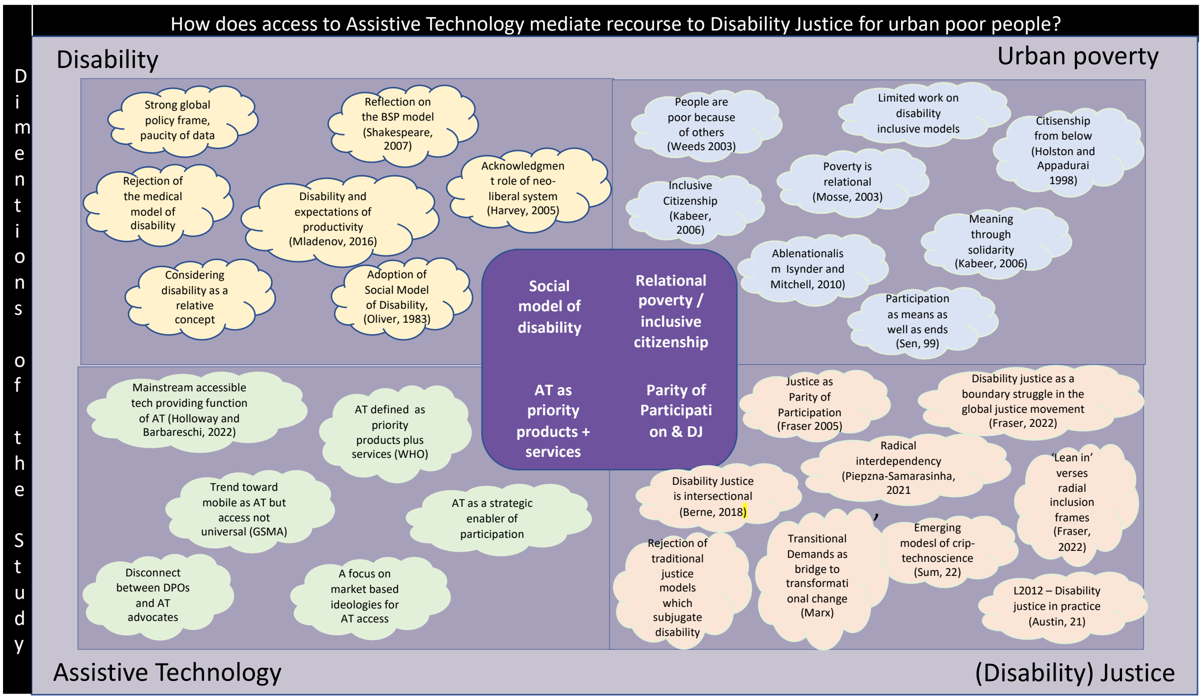


Figure 7: Core concepts informing the investigation

What emerges are a number of thematics, which find themselves repeating in each of the domain sub-sections; these relate to:

- A relational and socially constructed understanding of subjugation, both poverty and disability.
- The need to recognise intersectionality, interdependence and solidarity.
- The socio-economic context of neo-liberal capitalism, relating to the reification of productivity and marketisation of aid.

- Inclusive citizenship and activist practices as a tool to enable participation, valued for its own good, as well as in terms of what it can help generate in terms of claims making.
- AT – understood as priority products plus services - as a strategic enabler of participation.

To summarise these key points, I identify four overarching principles to guide the research, one related to each of the domains, but they overlap, of course.

These are:

- The social model of **disability**;
- A relational approach to **poverty**;
- **AT** as understood through the **priority-products-plus-services** approach;
- **Justice** as **disability-inclusive, participation parity**.

The core of these domains is justice because my central research question asks:

How does access to AT mediate recourse to DJ for urban poor people?

Therefore, in order to answer the question, I must set out what I mean by justice at the outset. Fraser's Parity of Participation is convincing because it takes account of the justice issues related to specific identities, but still keeps the connection with the neo-liberal backdrop that has proved relevant in the literature search. However, the justice framing is not disability specific and Fraser herself makes very litter reference to disability. Though various interesting attempts to address disability issues with Fraser's justice framework exist, for instance (Mladenov, 2016), it feels both intellectually and morally necessary to relate the core concepts to the autonomous calls for DJ, set out by the disability movement, to take account of the specific justice issues of disability. I will now move on to integrate the two, below.

3.1.3 Constructing a working definition of Disability Justice for the study

In order to construct a framework for justice, I am going to start from the basis of Fraser's Parity of Participation, following her Recognition, Redistribution, Representation approach. (Fraser, 2000). These three elements relate well to three corresponding aspects of the Sins Invalid, Disability Justice Framework, I have set out below in Table 3.

However, reflecting on the fact that Fraser's work is not disability specific, and building out from the core proposition of Sins Invalid, I add a further category of Disability Relations for the purposes of the study. This will capture the solidarity, interdependency and relational aspects specific of DJ and representing the other seven elements of the Sins Invalid framework (Berne et al., 2018). Fraser's framework is intentionally bivalent, and I do not pretend that there are no overlaps between the elements of Parity of Participation and a relational notion of justice, but the 'disability relations' element I have added are intended to relate to the disability specific elements of organising and empowerment within the disability community and between the disability movement and the wider movements for social justice. In short, the specific elements that are required to 'leave no body or mind behind', encompass *interdependence* (to meet each other's own needs in lieu of inviting further state control), *sustainability* (pacing, for the long term), enabling *collective access* through flexibility and creative nuance, balancing autonomy while being in community, moving together toward *collective liberation,* recognising *intersectionality, cross-disability* *solidarity,* and working between the disability movement and other movements for justice through *cross-movement organising* (ibid.). I understand that these seven elements boil down to three themes which I shall come to use in the empirical chapters, mainly **radical accessibility** and inclusive practices, **recognising intersectionality** within the disability movement, and **building solidarity** between the disability movement and other movements.

In the table below I set out these four disability justice elements, alongside a column hypothesising the role of AT in relation to this theme, to be tested in the data. The final column sets out a short definition about what DJ in this context might look and feel like, which will be tested and expanded in Chapter 7.

Table 3: Elements of an emerging model of Disability Justice to be tested in the investigation

An emerging model of Participatory Disability Justice to be tested in the investigation			
Fraser	**Sins Invalid**	**The role of AT …**	**Disability Justice is found when…**
		Tested in Ch 8	*Tested in Ch 7*
Recognition	**Recognising wholeness**: Disabled people are whole people. (principle 5)	***AT enabling Recognition***	**…disability identity is recognised positively,**
Redistribution	**Anti-capitalist Politic**: the very nature of our minds/bodies resist conforming to a capitalist "normative' level of production. (principle 3)	***AT enabling Redistribution***	**…disability poverty is tackled**
Representation	**Leadership of the most impacted**: to truly have liberation we must be led by those who know the most about these systems. (principle 2)	***Representation***	**…disabled people participate, set the agenda, and lead**
(Disability Relations)	**Inter-disability and cross-movement solidarity** **("no body/mind left behind")** [Summarised as: radical accessibility, recognising intersectionality, and building solidarity.}	***Disability Relations***: Solidarity, intersectionality radical inclusion	**…no body/mind is left behind in a broad-**

	Sustainability: we pace ourselves, individually and collected to be sustained long term. (principle 6) **Intersectionality**: we know that each person has multiple identities…that…can be a site of privilege or oppression…the very experience of disability itself is being shaped by race, gender, class and gender expression, historical movement, relationship to colonisation. (principle 1) **Cross-Movement organizing**: Disability Justice shifts how social justice movements understand disability and contextualise ableism, leading itself toward a untitled front politic. (principle 4) **Commitment to cross-disability solidarity**: We are committed to breaking down the ableist/patriarchal/racists/classed isolation between people with impairments who as "sick" or are chronically ill, "psych" survivors, and those who identify as "crazy," neurodiverse people, people with cognitive impairments, and people who are of a sensory minority, as we understand that isolation ultimately undermines collective liberation. (principle 7) **Collective Liberation**: How do we move together as people with mixed abilities, multiracial, multi-gendered, mixed class, across the orientation spectrum—where no body/mind is left behind? (principle 10) **Interdependence**: We see the liberation of all living systems and the land as integral to the liberation of our own communities, as we all share one planet. We attempt to meet each other's needs as we build toward liberation, without always reaching for state solutions which can readily extend its control further over our lives. (principle 8) **Collective Access**: as brown/black and queer crips, we bring flexibility and creative nuance to engage with each other…access needs aren't shameful – we all have various capacities which function differently in various environments…we can balance autonomy while being in		**based movement for justice**

	community…we can be unafraid of our vulnerabilities knowing our strengths are respected. (principle 9)		

Below, I will now show how this investigation is informed by this thinking.

3.1.4 A framework to answer the research questions

The diagram below shows how the **dimensions** of the study (Disability, Assistive Technology, Urban Poverty, and Justice) have given rise to the **framework** for investigation (which understands DJ as Participatory Disability Justice comprised of recognition, redistribution, representation and disability relations), in order to answer the research questions, across the **geographical distribution** (local, national, international), in relation to the **object** of the study (poor disabled people themselves).

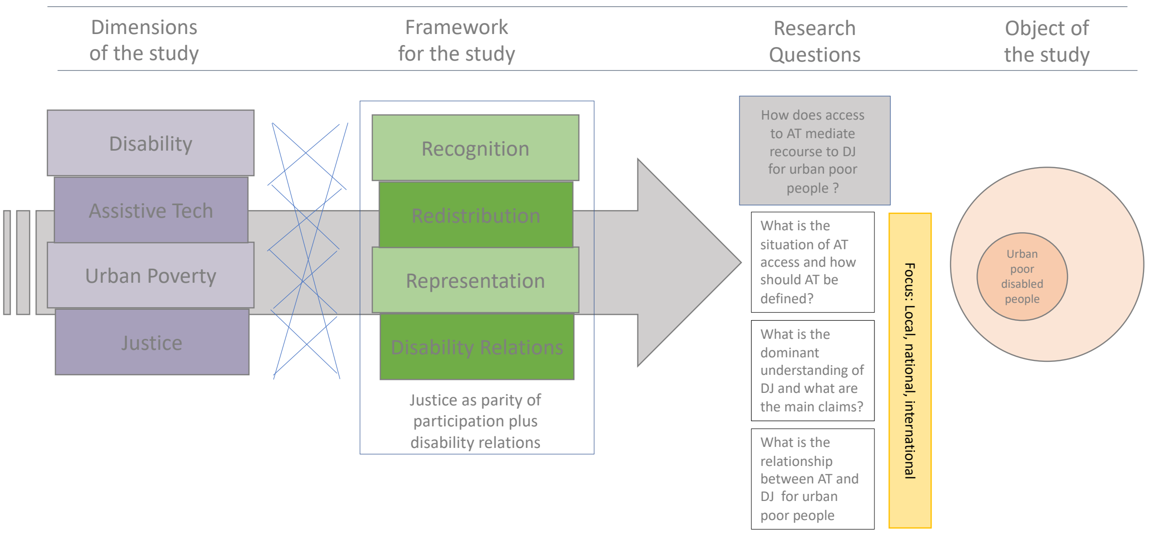


Figure 8: Participatory Disability Justice Framework for investigation

To offer the reader additional clarity on how the research questions will be answered, the diagram below sets out how the study will address these and how the framework relates to the ordering of the document, shows that the first two chapters (to this point) set up the framework and the later empirical chapters use it to arrange the data and analysis.

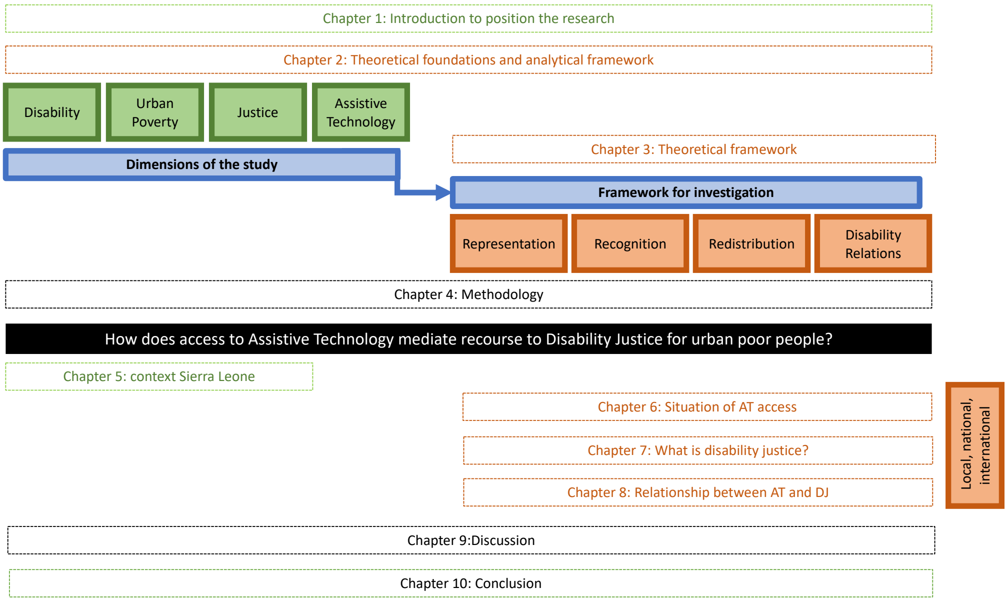


Figure 9: Thesis Overview

A caveat is necessary here. The concepts and context are complex and the data multifaceted. While every effort has been made to map the chapters to come to the framework as per the map set out above, for clarity and to test the thinking, it is not a perfect, tidy process. In particular the first empirical chapter (6) sets out a lot of data on AT access first, testing the assumption in the framework about what AT is, largely mapped geographically across the local, national and international spheres, and then the elements of the definition of AT. The discussion considers this in the context of the framing at the end of the chapter. This first empirical chapter rather sets the tone for the deep dive into justice that comes next in second and third empirical chapters (7 & 8) which discuss justice in more detail, and relate much more strongly to the justice framing, with each interrogating the assumptions given in Table 3. Chapter 7 considers understandings of justice geographically, then the claims for justice under the framework headings. In Chapter 8 the relationship between justice and AT is considered against the framework. Chapter 9 will discuss the framework in light of what is revealed in chapters 6-8, and will highlight the new definition of DJ on which to build. Chapter 10 concludes the study.

3.2 Conclusion

This chapter has taken the thematics assimilated as most vital to the investigation from Chapter 2, and provided an analysis of these concepts, choreographing a dynamic alignment of the ideas into a framework for the investigation. The chapter sets out how the dimensions of the study (Disability, Assistive Technology, Urban Poverty, and Justice) have given rise to the framework for investigation. I have called this framework Participatory Disability Justice and it is made up for four elements: recognition, redistribution, representation and disability relations. It is offered to be tested through answering the research questions across the geographical distribution (local, national, international), in relation to the object of the study (poor disabled people themselves). I will now move on to discuss the methodological approach for the work.

4 Methodology

4.1 Introduction

This chapter sets out the organisational approach of the study, exploring the methodology and selected methods for the investigation that follows. It will also explain the pivot required to adapt to the global COVID-19 pandemic. However, to begin, it is helpful to set the tone for the investigation, conceptually.

The ontological assumption adopted for this work was interpretivist – seeking an understanding of the world participants live in and respecting that there are multiple ways of viewing this, seeking to “establish universal generalisations to be used as pattern explanations” (Blaikie, 2003, p. 101). Through conscious reflection on what constitutes knowledge and its construction, this work was approached with a strong recognition of the contributions of disabled people in the case study settlements at least equal in value to ‘elite’, academic knowledge, or the contributions of policy makers or international actors. The disabled ‘participants’ (slum dwellers in Freetown) were intentionally both the first and the last to be ‘heard’ in the field work.

I have been fortunate to have been able to test some of the ways in which the research might inform teaching with our students of GDI Hub’s MSc Design, Disability and Innovation while undertaking this study. Therefore, I felt it was important on a principle level, that this work should make an active attempt to develop thinking which can lead to ‘social justice through pedagogy’ (Goodley, 2007), where research acts as the first point on the learning journey and informs teaching and learning (and the practice of this future leader). Socially, just research and pedagogy is important in a study which works from the assumption that participation is a pre-requisite to emancipation, not only, but particularly, because research and teaching are fundamentally a part of the struggle for participation.

My intention is that this work be both theoretically sound and practically useful (for the GDI Hub and the AT2030 programme and beyond), because it was funded as such, and because I believe in applying research to inform programmes for social change. I co-founded GDI Hub to bridge two gaps in Disability terms – the first between practice and the theory, and the second between Engineering and Social Sciences. That is to say, the purpose of this work is to intentionally locate and question the (engineering) intervention (in this case AT) within the context of the socio-political end goal (in this case DJ). I will offer more details on the research and its scope now below.

4.2 Research Objectives and Summary

4.2.1 Scope

Reflecting on the complexity this study seeks to consider at the intersection between disability, urban poverty, technology and justice, the following research objectives were designed:

- **To develop an understanding of the role of AT in supporting poor disabled people’s claims;**

- **To explore the role of AT, grounded in the context of those living in low-resource settings, and what else matters;**
- **To inform policy debate and practice at the local, national, and international level.**

These objectives were set out to inform the core research question:

How does access to AT mediate recourse to disability justice for urban poor people?

The overarching research question is answered in this study in relation to sub questions, set out below. Each of these sub-research questions is explored in an empirical chapter – 6, 7, and 8, respectively.

- ***What is the situation in relation to AT access globally, nationally, and locally. How should AT be defined?***

This is a 'first principles' question that is necessary to consider before answering the following ones. It might feel counter intuitive to define access to AT (at local, national, and international level) before defining AT itself, but this is indicative of the immaturity of the field, the complexity of the issue, and the state of the global debate. The WHO definition of AT is adopted as an assumption, but as the empirical evidence reveals, this is an incredibly loose and evidence-poor definition. One of the core questions of AT is what defines its boundary. As technology proliferates, and even if it does not, a social science enquiry (in the case of this PhD), or if fact, a Human Development intervention (donor funded under the SDGs) is poorly defined if the AT product itself is used as a measure of its impact. Certainly, in terms of AT this is very problematic, but very commonly done, as we shall go on to explore. In the latter part of the chapter, I suggest that AT might be better understood and offer a new definition.

This leads to the second sub-research question:

- ***What is the dominant understanding of Disability Justice globally, locally, nationally? What are the main claims for DJ of urban poor people?***

This question seeks to first map – from the data – the differing views on DJ, in order to understand if any settled consensus exists, and where the lines of disagreement lay. This section considered the very local response to DJ in the case study, considering what the specific claims of disabled slum dwellers in SL are. Then a broader consideration of what disability justice means follows in the context of broader data. Using my framework as an organising principle for the data– mapping the claims by Redistribution, Recognition and Representation, and Disability Relations helps to shape the conclusion. Through the empirical work I offer more context to the definitions of the elements of the framework for disability justice is developed.

Ultimately this follows on to the final sub-research question:

- ***What is the relationship between AT and DJ for urban poor disabled people?***

This question cuts to the core of the research and enables the dynamic relationship to be explored deeply against the analytical framework adopted. Again, the framework is the organising principle here for consideration of positive and negative correlations between AT and DJ, testing the assumptions in Chapter 3.

The discussion in this chapter functions to set up the final two chapters (9 and 10), which also consider the implications for policy and practice, as set out in the third objective for the study.

The framework established in Chapter 3 is set out below, again for ease of reference:

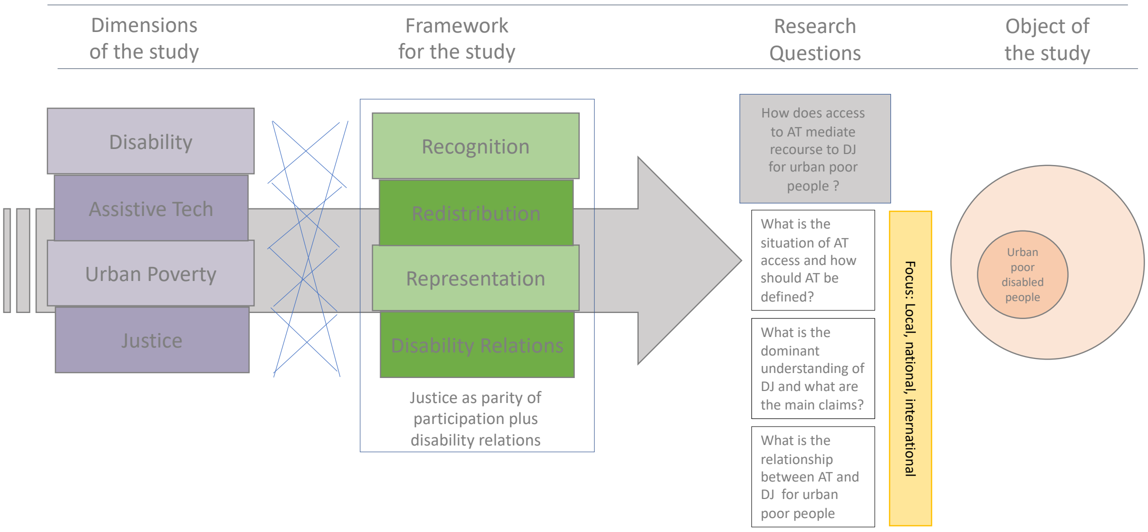


Figure 10: Participatory Disability Justice Framework for the investigation

4.3 Context and setting for the study

4.3.1 Global Disability Innovation (GDI) Hub

GDI Hub (www.disabiltiyinnovaiton.com) is a research and practice centre which grew out of the legacy of the London 2012 Paralympic Games (which I led for three Mayors of London). GDI is based in UCL Engineering, on the new UCL East Queen Elizabeth Olympic Park campus. GDI Hub has a mission to drive disability innovation for a fairer world, harnessing new technology but also non-tech creative practices and participatory approaches. We launched GDI hub at the Rio Paralympics in 2016, and I am currently the CEO of the Community Interest Company (social business) we established (in 2017). My co-founders are Professor Catherine Holloway of UCL Engineering (who is its Academic Director and leads the UCL research centre arm of our work) and Iain McKinnon (who is Director of Inclusive Design). Lord Chris Holmes of Richmond (nine times gold medal winning Paralympic swimmer and UK Parliamentarian) was our founding Chair and we have an Advisory Board led by disabled people from three continents. The institutions moving to East London post-Games, are our funding partners and also sit on the board – UCL, London Legacy Development Corporation (LLDC), University of the Arts London (UAL), Loughborough London LL), Saddlers Wells Theatre, and the V&A museum. GDI Hub considers six themes: Assistive and Accessible Technology, Innovation, Inclusive Design of the Built Environment, Inclusive Climate and Crisis Resilience, Cultural Participation, and Inclusive Education Technology.

To give a sense of size, as well as how quickly we have grown, GDI Hub now works in more than 41 countries with more than 70 partners and has a total programme worth of approximately £50m. As well as rapid growth, there have been many bumps along the way as we learnt more and more about 'what works'. We continue to work hard in service of a fairer world.

GDI Hub runs a Master's programme (though UCL, with UAL and LL), MSc Design Disability and Innovation on which I teach, and through which we continue to test our thinking and ideas - we think it is the first of its type in the world. GDI Hub at UCL is also the world's only WHO Global Collaboration Center on AT, which I co-direct with Professor Holloway. This status was awarded to GDI in 2021 for the work done on AT access and it is quite a prestigious recognition; yet along with it comes the need to think carefully about challenge.

4.3.2 AT2030 programme and partnership

In 2018, GDI Hub was asked by UK Government to co-ordinate a partnership including UCL, WHO, Clinton Health Access Initiative (CHAI), UNICEF and others to undertake a scoping report on AT (Holloway, 2018), which concluded that:

> *"The challenge of Assistive Technology is a complex web of market and system failure, compounded by a lack of participation from those that have the best knowledge of the issues (users themselves). This results in a supply/demand mismatch affecting almost a billion people, making Assistive Technology access one of the most pressing issues facing those that wish to see implementation of the SDGs by 2030.*
>
> *Any intervention that is to be successful must go hand in hand with policies and practices to remove stigma and discrimination and empower Assistive Technology users to take part at all levels of society. If the global community can get behind a single mission, enabling an environment where the holistic nature of the problem is acknowledged, innovation can thrive, and there is a willingness to fund large-scale strategic interventions based on what is shown to work, then there is much hope for success"* (Holloway, 2018, p. 7).

Alongside this, many co-development workshops were held with the partners, including Foreign Commonwealth and Development Office (FCDO) - then Department for International Development - in the UK to plan a £10m programme to tackle 'what works' on AT access. That became AT2030 and the funding was doubled in 2019, after six months, to £20m. GDI Hub sought to match that funding and has so far matched roughly half.

The AT2030 programme was announced by then Rt Honourable Penny Mordaunt, then Secretary of State for International Development, at the first Global Disability Summit co-hosted by the Governments of the UK, Kenya and the international Disability Alliance (IDA), on Queen Elizabeth Olympic Park in July 2018. It was announced at the same time as the formation of ATscale, the global partnership on AT, of which GDI hub was a founding member and funder. AT2030 will run until at least 2024 and so far it has 'reached' 28 million people through its interventions.

DPU-led Sub Programme 9 (SP9) of AT2030

The Development Planning Unit (DPU) at UCL (led by Julian Walker, supported by Ignacia Ossul and latterly Sylwia Frankowska-Takhari) has undertaken a study - Sub Programme 9

(SP9) of AT2030 – which was co-designed at bid stage by Julian Walker and me, to look at community responses to AT access. This has become a vital and well-respected piece of work within AT2030 which has now reached its conclusion (in December 2021). SP9 of AT2030 focused on four slum-settlements in two countries (Freetown, Sierra Leone and Banjarmasin, Indonesia). It is alongside the Sierra Leone aspect of this work that this PhD has been undertaken.

The PhD study in the context of AT2030

Phase 1 (in 2019- 2020) of this PHD research was undertaken alongside the first part of the DPU investigation for SP9 with shared research trips, partners, participants and even some shared workshops. Naturally then, some of the SP9 data was reinvestigated for this study and the initial work from this thesis was published in an initial paper in early 2021 (Austin et al., 2021a). The paper was led by me and was co-authored with the DPU and UCL teams.

Following a pause, made necessary by the pandemic, data collection in Phase 2 for the PhD (diverged from SP9) needed to be shifted to virtual data collection format for the PhD (as will be explained) with a broader international focus. A full summary of the datasets and my role as the researcher within them, is set out in more detail below. However, before this is considered in detail, we look at the case study itself.

4.3.3 Positionality and reflexivity

This work was undertaken by a female, queer, post-graduate, trained researcher who lives with two mental health conditions, and also works as the CEO of the GDI Hub CIC. This positionality required a great degree of reflexivity and accountability, as well as the transparency about positioning than the average PhD might.

The following Table 4 sets out some of the risks and how they were mitigated.

Table 4: Risk and mitigations of risk within this thesis

Risk	Mitigation	Comment
Complication due to mulitple roles	• VA undertook first year of PhD study at DPU quite seperatly from GDI Hub work, setting tone and scope autonomously of the professional role I hold. • Supervision (by JW) was supported by a second supervisor (HY) who had no connection to AT2030. This proved invaluable. • Shared research trips and strong communication mechanisms in Phase 1, and continuing communication on data use between JW and VA supported clarity of data shows.	This was made easier by the decision to collect additional (non-shared) data in 2020 (Data D). The addition of internationl interviews, gave seperation between the PhD research and the wider AT2030 Sub Programme 9 research objectives.
Unfair 'advantage' due	• Seperation of AT2030 programme management (of DPU) and VA role	All steps were taken to avoid any unfair

to position as AT2030 Director	at CEO after 2020 – PM role given to Senior GDI Staff member (Joel Burman). • All operational decision making on DPU AT2030 SP9 project led by JW and team at DPU, not VA or GDI.	advantage due to positionality, in some cases the multiple roles sought to complicate rather than aide. On reflection I think we managed this well, together.
Implicit 'power relations' affecting data collection	• Specifically in relation to the AT2030 Advisory Board interviewees (Data D), it was necessary to ensure that answers were driven by honest opinion not funding concerns. It was for this reason that anonymous interviews were undertaken, interviews were recorded in private, and it was made clear that there was no link between funding decision and interview inputs. • Funding decisions on AT2030's main grant had already been made at the time of interview.	I know many of these colleagues well, but there is not a one way power dynamic. Many of them hold very senior global roles. They are well used to (as am I) managing multiple, complex roles with individuals in differing settings. Ethical approval also required this interviews to be anonymous, as part of the broader investigation into GDI Hub's AT2030 progarmme.
Academic freedom, political restriction and funding concerns	• The AT2030 programme is funded by the British Government to find out 'what works' in getting AT to the people that need it around the world. But GDI has maintained from the start academic freedom is important, and never has FCDO sought to curtail or question that – in fact the opposite has been encouraged. • Data driven thinking and an inductive approach enabled me to start far from any political narrative, and rather to center the slum dwellers views from the start. That paper was published early on, enabling the learning to be the basis of the integration to the second phase.	Despite this appearing to be potentially problematic it has not been, yet. In fact, any impact of the research on funding questions would not be likely to arise until after publication, if dissemination is successful.

	- The robust research methodolgoy ensured analysis was sound and robust.	
Isseus of personal identify and the study	- Queerness in a non-queer friendly country was an early concern. This was managed through risk assesments, and safety measures and sensible precautions, working closely with the local team. - Misogyny is always a reality, again this was tackled through clarity, persistance, and collective working. - My impairments (mental health conditions and later, Long Covid) simply had to be managed – this prolonged the study by about a year, probably. Though it's hard to say as 2020/ 2021 were difficult for everyone. - 'Owned' positionality, clarity of methodology, open and transparant robust process supported all of this.	One reflection; despite having a disability identity related to living with two mental health conditions, my status was assumed as 'non-disabled' by participants where it was mentioned. I was also assumed to be straight. I corrected neither automatically, as per the risk assesment. This is not intended as anything other than an observation about the role of identity in culture and the thesis explors this further in various ways. Methodologically, it also offers a personal narrative which I have often refered to in my research notes.

As highlighted above, a number of these issues of positionality led to direct and necessary transparency – the most important aspects of which were the owning of positionality, appropriate choice of methods and anonymisation, sensible and clear assessment of risk, separation of roles in AT2030, and open communication. The role of my second supervisor, as someone outside of the AT2030 programme, is also of note and was valued and vital.

4.3.4 Case study setting: Freetown, Sierra Leone

4.3.4.1 City Selection – AT2030 and the PhD

Scoping work in Freetown was undertaken by the author, as part of AT2030 in early 2018 when I held scoping interviews and discussions with over twenty stakeholder organisations in Freetown to inform research development for AT2030 overall. The choice of location for the focus of the SP9 study was determined in 2019 by a sub-group of AT2030 project team led by Julian Walker at DPU, UCL (including myself). The decision to work in Sierra Leone (alongside Indonesia for the second case study in the DPU project - not a focus in this research) was due to the conditions of informality and urban poverty, the need for but evidenced lack of AT, and the longstanding and beneficial trusting relationship between UCL DPU and the local partners most especially the Sierra Leone Urban Research Center (SLURC). It felt important that the 'point of entry' for the SP9 work, and also mine, was via organisations of the urban poor, not disabled people's organisations, precisely because the latter often do not work on urban poverty (nor the former on disability) and given the DPU's specialism we wanted to see what we could learn from this alternative approach. We brought in Leonard Cheshire (LC) to the partnership in the early phases of the project to connect to existing Disability work in Sierra Leone, and later took on a consultant that had led this research for LC. These longstanding partnerships and ability to form a bridge between disability and poverty work in Freetown were important since the topic at hand was complex and the time scale fairly limited. The focus location for this study then became Freetown, Sierra Leone as it met the criteria for the research. A full overview of the context in Sierra Leone is presented in Chapter 5.

4.3.4.2 Settlement Selection

For this study, I initially worked with disabled people in two informal settlements in the City: Dworzark and Thompson Bay – which are mixed settlements with representation from disabled people among the populations who were largely made up of non-disabled people. As I set out in more detail below, latterly HEPPO settlement was added. HEPPO is an autonomously organised residential area, settled only by disabled people and their families.

SLURC were the local partner. For this research, SLURC facilitated access to the settlements through the Federation of the Urban and Rural Poor (FEDURP) and their partner, the Centre for Dialogue on Human Settlements and Poverty Alleviation (CODOHSAPA). The settlement selection - initially including only two Dworzark and Thompson Bay was led by FEDURP, in consultation with the communities that lived there in 2019. I was present for these discussions including community meetings in the settlements.

The HEPPO settlement was engaged later, after being interviewed by the DPU project team as part of the first field trip when Julian Walker was leading a piece of research with CODOHSAPA on Informal Markets for AT (also commissioned as part of AT2030). HEPPO was then added to this PhD research because of the immensely different and interesting context it offered. Some more information about the settlements now follows.

Dworzark is known as Freetown's largest settlement, sprawling up the steep hillside overlooking the city, and comprising an estimated 16,500 people in approximately 5000 households (SLURC, 2018a), built since approximately 1940 and households hold approximately 7 people (SLURC, 2018b). Informal markets, hostels, religious and community centers, bars and cafés are found further into the settlement with a formal health center sitting at its entrance. We worked in an area rising up the hillside along the central roadway called Brazil, which included the main road through the settlement, with pathways and uneven tracks splintering off from it, scattered with self-built homes, largely shacks and shelters.

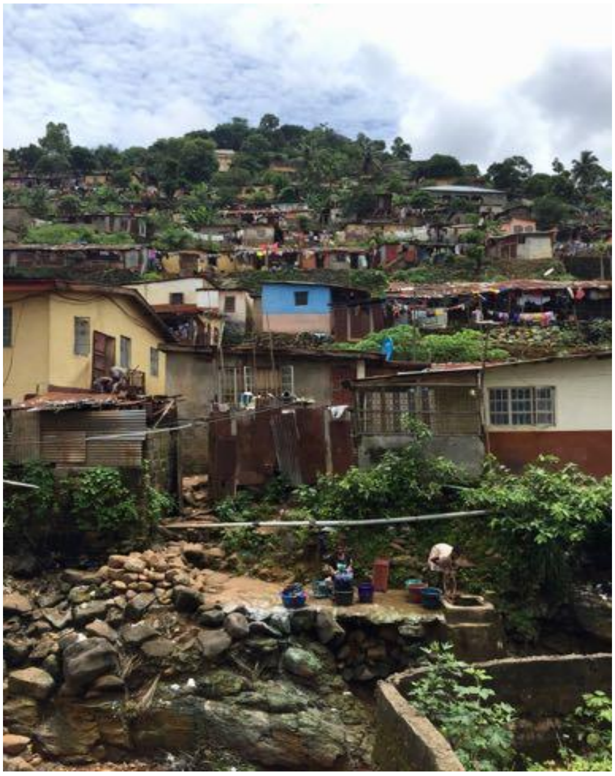


Figure 11: Dworzark settlement rising up the hill in the centre of the city (source: Author)

Thompson Bay, comprising 6000 residents, is a much smaller coastal settlement, slightly further from the center, which spreads into the estuary as new occupants arrive and build in increasingly precarious conditions.

Figure 12: Thompson Bay settlement: the market (left) & building out into the estuary on sandbags (right). Source: Author

Thompson Bay is also an unplanned settlement, comprising of self-built, informal structures without access to running water or regularised sanitation. These particular settlements were chosen for relevance, e.g., persons with disabilities were present in the communities, and for the communities' own interest in building their demographic data around disability which could be used as an advocacy tool. FEDURP uses this data as part of their wider commitment to advocacy though 'information as power' and much of it can be viewed on the federations' international website (SLURC, 2018). This participation in enumeration is part of Slum Dwellers International's (SDI) model of building collective agency and evidence to support their claims (Tomlinson, 2017).

HEPPO

While the settlements of Thompson Bay and Dowrzark are both 'mainstream' settlements of urban poor people, without any targeted facilities for, or organisation, of disabled people, the HEPPO settlement is different in that it is a community that was constructed by disabled people for themselves and their families. HEPPO stands for Help Empower Polio Persons Organisation and the group is made up of households of disabled people who came together to squat the land next to the Prison in Pademba Road in 2000. HEPPO has registered itself as a Disabled Persons Organisation (DPO), and it has had some success in lobbying against eviction at the time of writing, as we shall see in later discussion.

Figure 13: Esther, the female chair of HEPPO, in the settlement. Source: Angus Stewart

The settlement area is smaller, and much more central, and the homes are constructed of temporary materials such as corrugated iron and wood; it also contains a small church structure which functions as a community space. The settlement is too small even for an informal market, though is centrally located to Freetown's markets and across the main road from Dworzark. Despite proximity, the Settlement Dewllers did not mix between

HEPPO and Dworzark, potentially due to the latter's physical inaccessibility up a large sprawling hill. Many HEPPO residents undertook begging activities for livelihoods on the main road outside the settlement and around the City.

4.3.5 Methodological approach

"An inclusive approach to research implies that people who are marginalised are deliberately and actively brough into processes as citizens who have equal rights to be included and heard alongside others" (Wickenden, 2021, p. 321). Following this, and building on the work on participatory research practices by (Chambers, 2013) and (Freire, 2000), initially this study design intended to reflect on the principles of Disability Emancipatory Research (Deepak et al., 2014). As far as is possible within the context of a PhD study, it was anticipated that building in co-design (including co-authoring of papers and participation in the analysis) would enable a participatory approach and build community capacity. In addition, participatory methods would provide opportunities and insights 'in ways that can foster shared learning as well as outputs that can advance the claims (of vulnerable groups)' (Fernandes et al., 2017).

Firstly, then, a Participatory Action Research methodology - Disability Emancipatory Research (DER) - based on Deepak's work, was explored in depth. This approach centers the participation of disabled people as researchers as well as participants through supporting the engagement and training of disabled people in the research process. I was attracted to this due to the obvious benefit of enabling an emancipatory positionality; the opportunity to build capacity among disabled slum dwellers as co-researchers, and a flexible research methodology which can be adapted according to the contextual struggles of the community.

However, even before COVID-19 stopped international travel, it was a problematic approach because though local teams would remain connected to the work, a long-term partnership, visits specifically for this PhD study would be limited to three, plus a scoping visit, meaning that a pure action-research approach would be difficult to manage, justify and deliver. COVID-19, in reality, would have made it less possible still. In considered consultation with supervisors, it was concluded that adopting a pure DER framework for a PhD at this time would be too problematic due to ownership of data and work being one's own.

Secondly, Grounded Theory (GT) (Glaser and Strauss, 1967) was explored and particularly Constructed GT (Charmaz, 1996). As Charmaz argued *"A grounded theory analysis starts with data and remains close to data"* (ibid., p.28) and this was appealing for two reasons: one, the relative paucity of existing data in the nexus of 'disability-informality, AT-justice' which centers the voices of the urban poor, and two, the opportunity to 'enter the field' without a preconceived theoretical perspective into which to 'slot' the words and meanings of poor, disabled people whose voices have been hidden for so long. Through her approach Charmaz suggested that the preliminary appreciation of the literature is part of a balanced approach to navigating the beginning of research questions, pointing out that it is infrequently the case that funding bodies and ethics committees will allow research projects to begin with no foundational literature survey, however preconceived ideas must not drive the data. This is *"a compelling reason for many researchers (particularly PhD students) to undertake a preliminary review"* (Giles et al., 2013, p. 36). Furthermore, it is understood that "*If used reflexively, a preliminary literature review can enhance grounded theory research* *without defining it*' (ibid., p.38). Thornburg and Thornberg's 'Informed Grounded Theory' (Thornberg and Thornberg, 2012) presents one set of tools which help with "*adding literature review strategies to the GT research approach*" (ibid., p.243). They argued that:

> *"Grounded theorists have to accept the impossibility of pure induction and at the same time recognise the power of the constant interplay between induction (in which he or she is never tabula rasa) and abduction…the ability to draw good abductive inferences is dependent on the researcher's previous knowledge and rejection of dogmatic beliefs and development of open mindedness"* (Thornberg and Thornberg, 2012, p. 247).

Informed GT strategies, are – it is suggested – useful beyond pure GT and tools, and include theoretical agnosticism (seeking the cracks between theories), theoretical pluralism (beyond orthodoxy, avoiding 'pet codes'), theoretical sampling of the literature (to saturation), staying grounded (with the data), theoretical playfulness (allowing for Charmaz's "whimsy and wonder" (Charmaz, 1996, p. 136), memo-ing extant knowledge associations (allowing idea to emerge), and constant reflexivity (together with reflexive memo-ing; (Thornberg and Thornberg, 2012, pp. 250–255).

However, at the time of upgrade (in late 2019), it was felt that since I had conducted a Masters in a similar field, and work day-to-day in the space, it was not suitable to operationalise a GT methodology as I have extant knowledge which should be made explicit. I accepted this because it would be illogical for the choice of methodology to overshadow the data or the findings, since this would be counter intuitive to my intention of centering the voices of slum dwellers themselves. Ultimately, then, because of the complexity of the case and the desire to spend time debating the topics and findings, not the validity of the methodology ad infinitum, some of the principles and tools of these GT-informed strategies were adopted by this study, without claiming this as a GT methodology.

Hence, this research uses a straightforward **Thematic Analysis (TA)** and a six-stage approach was adapted from Braun and Clarke (Braun and Clarke, 2006):

I. Familiarising oneself with the data (collection, transcription, re-reading)
II. Generating initial codes from the data
III. Searching for themes across the data corpus, and data items
IV. Reviewing & testing themes (including memo-ing and theoretical sampling)
V. Defining and naming themes
VI. Producing final analysis (thesis)

TA has been previously critiqued for the fact that *'[it] is a poorly demarcated, rarely-acknowledged yet widely-used method'* (ibid.) which often lacks rigor and therefore credibility. However, TA is a flexible way of "theorising meanings" (Holloway and Todres, 2003) in relation to lived experience, or what Blakie might call seeking to "establish universal generalisations to be used as pattern explanations" (Blaikie, 2003, p. 101). Given the complexity of the case study and topic, with some shared data, and the added issues caused by the pandemic, a straightforward methodology was the prudent choice and I selected it, intending to undertake this in a participatory way returning to SL to support the coding and analysis with stakeholders and the slum dwellers themselves.

4.4 COVID-19 pivot

The Pandemic rendered return visits to SL impossible after the end of 2019, and in fact I contracted COVID-19 on the day I was supposed to travel in early March 2020 (which has had a long-term impact on my health).

Managing a truly participatory study in all datasets became impossible especially since the resources of local partners had to be diverted, often to critical life-saving activity (e.g., giving out rice to families of disabled people who had no source of income).

In general, it is worth noting that the inability of the Global North researchers to ‘fly around the world’, as one senior global expert interviewed in this study put it ‘with their superhero capes on’, has the potential for some considerable benefits for justice, power relations, participation and the wider AT2030 programme. In fact, the DPU were able to build considerable local capacity to conduct research on the SP9 project.

But for a PhD study where the core researcher is unable to travel, it was more tricky, and ultimately too resource intensive to develop fully participatory processes with the disabled slum dwellers at the time. It is also worth noting that the lack of technology played a direct role in this, neither the slum dwellers or the stakeholders had access to the type of tech the rest of the world was turning to in the initial stages of the pandemic, as the DPU’s research in phase 2 found (SHM Foundation, 2022).

I had to accept then, that although much of the work undertaken pre-pandemic was participatory (particularly the AT2030 work re-investigated for this study), it was not possible to hold timely group workshops of slum dwellers to for instance undertake coding, present findings, or revise or determine coding patterns. It is regrettable and a limitation of this work (discussed in Chapter 8), to partially mitigate the fact that this is not a participatory methodology, and the fact I was not able to refer back to the participants in the analysis and coding process. I chose to complete and publish the initial study with slum dwellers (Data A) mid-way through, in 2021, allowing the themes of this analysis, to inform the rest of the research (Austin et al., 2021a). While not the participatory approach that I had initially wanted to undertake, it did at least allow the themes form the slum dwellers’ own experience to set the tone for the rest of the investigation, especially with global experts.

I have not considered the impact of COVID-19 specifically in this study due to the fact it had begun, and the research started before the pandemic hit. Still, I have to note that methodological changes aside, speaking about it without acknowledging the impact on the disabled people feels wrong. It has been differentially difficult, and the need to develop inclusive and resilient systems for AT provision becomes even more important (Smith et al., 2021).

This was not the only way COVID-19 changed the study. It was the initial intention to be solely concerned with the experiences and views of slum dwellers who were disabled people in the settlements in Freetown. This group is termed as the primary participants (Participants) of the study and remains its central concern. The initial scoping trip in 2018 and first research trip in 2019 were undertaken under this assumption. This became Phase 1 of the research.

However, in the week of the second planned visit to Sierra Leone (March 2020) the university stopped all international travel. This continued for 18 months and was combined with the fact Sierra Leone launched a 12 month ‘State of Emergency’ and that my sickness (with Long Covid) restrictions continued to hamper the research. At the time data collection and analysis was completed (end 2021), SL remained on the Red List for UK travel, with university travel still not allowed, preventing a return.

This resulted in a pause through the middle part of 2020, which was unwelcome at the time, but on reflection brought some considerable benefit, because:

(1) it allowed for analysis and interpretation of the initial data from phase 1, publishing this work alongside the thematic framework from the initial data from the slum dwellers themselves, which

(2) It enabled the evidence from phase 1, (focused on the participants' voices as explained above) to inform phase 2 planning and investigation.

It has helped me recover too, which mattered.

What also became apparent from the initial analysis was that in order to understand the realities of AT and justice for slum dwellers in Freetown, national and international policy and practice were incredibly relevant. While this had not been designed to be an initial theme of investigation, the moment of reflection enabled a re-think. The study was therefore adapted in the first part of 2021 to solicit more evidence from national and international stakeholders; this became the phase 2 of the research, which was made possible by the availability of virtual tech, a benefit due to the way the world has adapted to COVID-19 if one was lucky enough to access the tech needed to support it. Thus, the COVID-19 pivot also enabled:

(3) Phase 2 of the research to maximise the opportunity for virtual (online) interviews and gave access to senior international and national policy makers who would not have been able to participate, otherwise.

Therefore, this thesis presents data in two phases, across six data sets, collected over three years, as set out below. More detail on the data collection is included below.

4.5 Data Collection

This is a qualitative study using mixed methods (one quantitative survey) and this thesis uses data from six datasets as evidence tessellated toward providing a clear narrative based on robust evidence. The datasets are presented in the table below, as follows:

Table 5: Datasets linked to methods and chapters

Datasets	Collection and Analysis	Methods	Empirical Chapters
PHASE 1: 2018-2019			
Data A: Participant and stakeholder interviews and events 2019 - 2020 disabled slum dweller participant interviews (16); and stakeholder interviews with	Collected and analysed by VA.	Interviews, Workshops, Events,	6,7,8

supporting organisations (5); events (4)	Data collection at two events in 2020 by SLURC.		
Data B: AT2030 local data • Dworzark and Thompson Bay's settlement research study • HEPPO settlement study • Rapid AT assessment (RATA)	Collected DPU, analysed by VA	Survey, interviews, participatory workshops, participatory photography, shadowing.	6,7,8
PHASE 2: 2020 – 2021			
Data C: International and National Studies, Policies • Informal Markets study AT SL, 2019 – DPU • Country Capacity Assessment AT SL 2019 - CHAI • SL AT policy (and launch event) 2021 - GoSL • SL Priority Assistive Products List 2021 - GoSL • WHO GREAT summits (2017, 2018, 2019) – WHO • Product Narratives	Collected various, analysed VA.	Interviews, workshops, events, discussive papers, talks.	6,7,8
Data D International Interviews 2021 Interviews with (10) global leaders of AT.	Collected and analysed by VA	Interviews conducted remotely.	6,7,8
Data E Remote participant interviews 2021 Re-interviewing initial participants and stakeholders (5)	Collected and analysed by VA	Interviews conducted remotely.	6,7,8
Data F: Field Notes Scoping notes from 2018 trip and field notes from leading AT2030 programme since 2018	Collected and analysed by VA	Notes made by VA over the years of the AT2030 programme.	6,7,8

There is some overlap within the data collection dates but the phases are shown when I engaged with the data collected, if collected by others.

Phase 1: 2019 – 2020

Data A: Initial Interviews conducted with 16 Slum Dwellers in Dworzark and Thompson Bay settlements, and interviews with 5 stakeholders (by VA). The slum dwellers were identified through the Rapid AT Survey (conducted by the AT2030 SP9 team), and the stakeholders were selected by snowball sampling identified by participants.

Data B: **AT2030 local data** consists of three elements collected by the AT2030 SP9 team and was reinvestigated by VA for this study.

- A rapid AT survey of Dworzark and Thompson Bay, using the WHO RATA tool
- AT2030 focus groups and workshops (six in each in Dworzark and TB)
- A RATA and qualitative survey of HEPPO, an autonomous community, and an interview with HEPPO (by VA).

Phase 2: 2020 – 2021

Data C: National Policy & studies undertaken by CHAI (SL Country Capacity Assessment using the WHO tool) and DPU (Informal Markets Study) respectively in 2019, both commissioned by VA as part of GDI hub leadership of AT2030. Later in 2020/ 2021, the Government of SL also produced an Assistive Technology Policy, and AT priority products list (APL) with support from the AT2030 programme. Finally added to this list is the AT Product Narratives, published by AT2030 and AT scale and produced by CHAI. These studies were reinvestigated by VA for this study. The policy content of the three global WHO AT conferences was also considered here (2017, 2018, 2019).

Data D: International Interviews undertaken by VA, remotely, during the middle of 2020. Interviews with eight global leaders (a subset of the AT2030 board) were supplemented by two interviews with leading international disabled persons representatives (from the WeThe15 board) resulting in ten interviews in total of global leaders, selected for diversity of social identity and location.

Data E: Participant and Stakeholder interviews undertaken by VA, remotely, at the end of 2021 comprising six participant interviews (two from each settlement, including HEPPO).

Data F: Field notes of the author, since 2018 when AT2030 scoping work took place, I kept reflexive diaries. These notes have been used only where they provide vital and core evidence. This was only used where reflections are critical to the findings.

4.6 Data Analysis

4.6.1 Definitions

Local: **refers to the community level, relating to the settlements individually or in combination across the City** – the conditions or experiences of the community as defined as the individual settlements, Dworzark, Thompson Bay and HEPPO. Evidence at this level relates to the experiences of disabled slum dwellers as impacted by local (informal and formal) governance, activities, and resources, beneath both the national and international levels. Occasionally, where community level conditions are common, they were considered across the City, though it is indicated where this is the case.

National: refers to country level, relating to Sierra Leone. The conditions or experiences reported at this level are encompassed by formal nation state boundaries, governance, and national legislation, as well as conditions and social mores which are evidenced as common across SL. This is above the local level and below the international level.

International: relates to policies and practices that are designated at an international or global level. The focus of this study has limited this evidence to persons already engaged with AT and disability at a global policy level; often leadership falls within the UN system. It is above the local and national levels.

4.6.2 Phase 1 data interpretation - Initial Analysis

Patterns emerging from the initial Participant data (A) were sought using inductive analysis and was correlated with data B and C for an initial paper (Austin et al., 2021a). Building out the themes of the initial empirical work with the settlement dwellers as the primary data source first, before adding the national and international investigations enabled an acknowledgement of the ‘grounded’ principles I hoped to work with. Some of the tools of Grounded Theory (such as memo-ing, keeping a reflexive research diary) to draw out initial themes and code ideas, were used. Initially 28 codes and five themes were identified from data A and they were used to investigate the data B and C. This resulted in a slightly evolved set of codes and themes, which were published in the resulting paper.

Phase 1 data collection therefore, resulted in an analytical framework informed by the analysis of the transcripts of interviews with the Participants themselves, published in (Austin et al., 2021a). This set the tone for the discussion with international and national stakeholders. The framework is reproduced here in Figure 14.

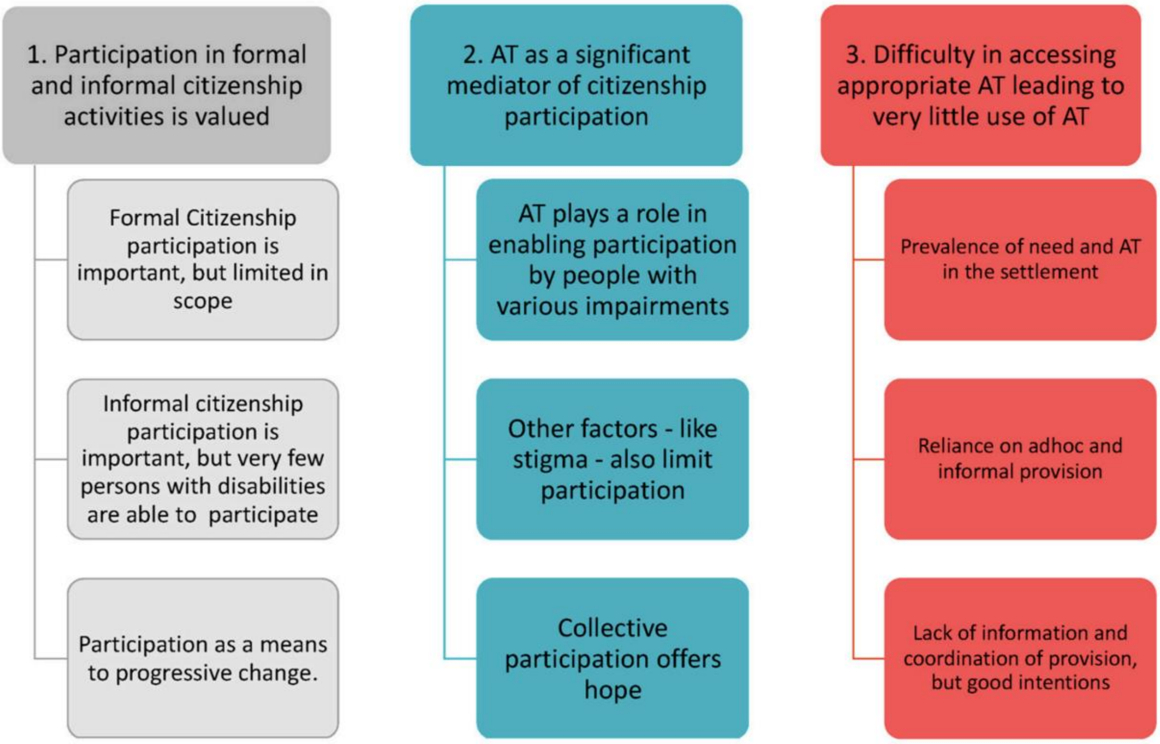


Figure 14: Framework resulting from Phase 1 data collection (Austin et al., 2021)

In stage 2 of the research the intention was to build new evidence from the data collected with international, then national stakeholders, while continuing a 'conversation' with the stage 1 themes. Ultimately, the Participants in the settlements were returned to in data E, to verify and steer the findings in an informal way. This worked well, with the thematics in Figure 14 used to inform the topic guides for data collection with datasets D and E. It was also important to explore latent as well as semantic themes (meaning beyond the surface) recognising the social construction of those meanings in their given context, by contextualising date with various methods and sources across the datasets. I did this through manual coding of the two data sets (D and E).

As mentioned, there is no pretence that the data collection or analysis were approached in an 'epistemological vacuum' (as would be necessary for pure grounded theory), given the Master's degree, work experience, as well as literature search informed thinking from the start. However, as Dey (1993) argued there is *"a difference between an open mind and empty head"* (Dey, 1993, p. 63) and thematic analysis was used here in such a way that let the data from the Participants 'talk first' from stage 1 to stage 2.

4.6.3 Summary of Data Collection and analysis

A summary is presented in accordance with the COREQ guidelines for reporting health research (Booth et al., 2014) which was chosen to enable a robust presentation of various data sets.

	PHASE 1		PHASE 2		
Dataset	A	B	C	D	E

COREQ measure	Local Participant and Stakeholder interviews 2019	AT2030 data: • RATA • AT2030 workshops • HEPPO 2019	National and International AT Policies • Studies • Policies • Summits	International interviews 2021	Final Stakeholder and participant interviews 2021
Role of VA	Collected & analysed data	Participated in some (few) aspects of data collection and re-analysed data	Co-designed research; commissioned studies and re-analysed data	Collected & analysed data	Collected & analysed data
Data collected by:	VA	AT2030 (SP9) team	AT2030 Team (CHAI and DPU); GoSL; WHO	VA	VA
Participant selection (sampling, methods, size, non-participation)	N=16 (female 50/50male) participants selected from RATA; 5 stakeholder interviews; (f70/30m) 4 events.	N=4256, house to house survey using WHO RATA tool, FGD, photo diaries and shadowing.	Various	8 experts selected from AT2030 board and supplemented by 2 disability experts from WeThe15 board. (f50/50m)	6 interviews with participants and stakeholders form initial dataset A. Chosen on access and availability. (f50/50m)
Setting (location, presence of non-participants, demographics)	Informal settlements, Freetown, interviewer translator and transcription support present,	Informal settlements, Freetown, data collectors and occasionally project manager present	Various across SL, and globally Various across SL, (Freetown and Bo), CODOHSAPA provided transcription/ translation	Online	Online

Data collection (interview guide, recording, duration, transcripts, saturation)	Semi Structured Interviews (SSI) in Krio (local language) or English; recorded by i-phone, duration 30-60 mins, transcription by SLURC team.	House to house WHO Rapid AT survey using Kobo Collect, duration 20-30 minutes. Transcription and translation by SLURC. Workshops by SLURC/DPU, duration 60-90 minutes, refreshments provided, transcription as before.	Secondary analysis of data.	Remote (using teams/zoom) Semi Structured Interviews in English (SSI) lasting 60 minutes each, with global leaders - a subset of AT2030 board - using a topic guide guide, recorded by OtterAI transcription by VA.	Remote (using teams/zoom) Semi Structured Interview (SSI) lasting 30-60 minutes each, in English; recorded by Otter AI transcription by VA.
Analysis and findings (coding, themes, software, participation checking)	Coding by VA, using manual coding.	Re-investigation of data by VA using manual coding.	Re-investigation of data by VA using manual coding.	Coding by VA, using manual coding.	Coding by VA, using manual coding.
Reporting (quotations, consistency, clarity on themes	Analysis in phase 1 reported in published paper (Austin, 21)	Analysis in phase 1 reported in published paper (Austin, 21)	Some analysis in phase 1, supplemented by phase 2 analysis, reported in (Austin, 22)	Some analysis in phase 1, supplemented by phase 2 analysis, reported in (Austin, 22)	Some analysis in phase 1, supplemented by phase 2 analysis, reported in (Austin, 22)

4.6.4 How the data was analysed

To summarise, it is helpful to consider the flow diagram in Figure 15 below. This shows how the Phase 1 datasets informed the initial theoretical framework published in Austin et al, 2021. This was arrived at via thematic analysis using software (Atlas) to derive patterns from the data showen in datasets A, B and C.

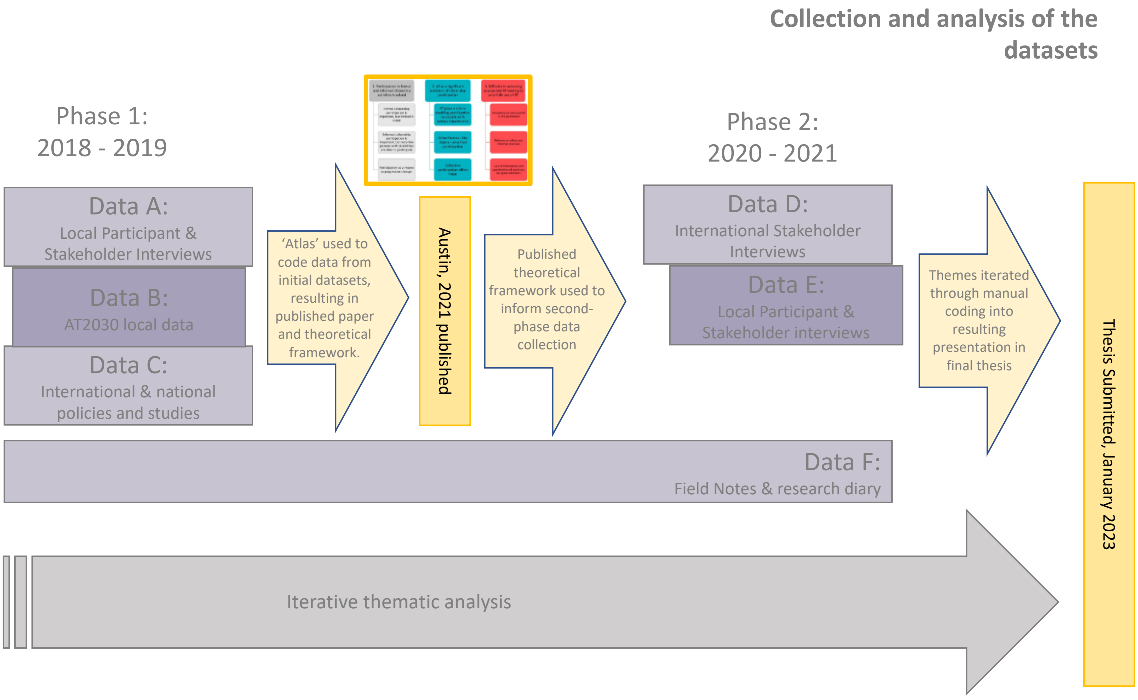


Figure 15 Collection and analysis of the datasets

These themes then informed the topic guide for phase 2, where the themes which had arisen from the local and national data were tested at an international level, then the local participants and stakeholders were interviewed, to further refine the emerging story. After stage two was complete, manual coding of the new data allowed the themes to be further iterated, and a return to the literature supported this process. The final resulting iterated themes were then structured into the format shown in this thesis through the chapter structure, in a way which was both true to the data and made sense to the reader. I shall now outline that structure, below.

4.6.5 Structure of the thesis

As the reader will already have noted, Chapters 1 and 2, present the introduction and background literature with Chapter 3 presenting the framework, and this chapter (4) is the methodology chapter. Chapter 5, next, offers a contextualisation of the country, Sierra Leone. This is followed by the empirical chapters (6,7,8) then the discussion (9) and conclusion (10) which are designed to answer the research questions directly. This is summarised as follows:

- **Chapter 6: AT** answers the question: what is AT, how available is it to urban poor people in Freetown, and what is it used for? The first part of the chapter draws heavily from the existing understanding of AT before considering what AT means at a local, national and international perspective. The second part of the chapter relates the evidence of AT uses to the conceptual framework before concluding with an undated view of *'AT for what'?* and offers a new definition of AT.

- **Chapter 7: DJ** then relates to dominant understandings of DJ, at the local, national and international level, before considering these notions in relation to the claims for (disability) justice poor slum dwellers in SL and synthesises the findings against the conceptual framework, concluding with an expansion of the understanding of DJ.
- **Chapter 8: Relationship between AT and DJ** then relates to evidence of how AT relates to DJ at each geographical level and in relation to each aspect of the framework and an analysis of how the (mis) framing of AT can impact recourse to DJ. It concludes that AT is a *transitional demand* of DJ.
- **Chapters 9 & 10: Discussion and Conclusion** discuss these findings in context and offer implications for policy before considering limitations and concluding.

The following diagram (Figure 16) functions as a thesis document map.

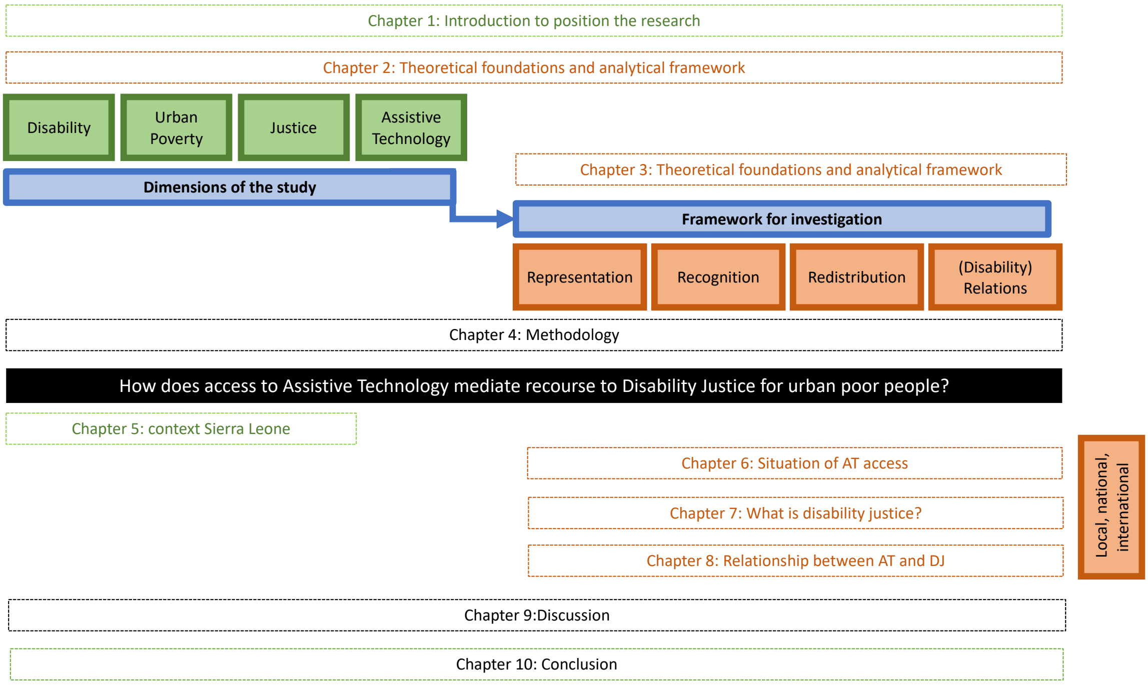


Figure 16: Thesis map

4.7 Ethics & Accessibility of the Research Process

The studies in this research have ethical approval under two UCL AT2030 projects. The first, is the Sub Programme 9 DPU project: “AT2030: build capacity and participation driving community-led solutions” (15367/001) which run from May 2019 to the end of 2021; Professor Julian Walker is Co-I, and the Principal Investigator (PI) for this sub-programme, Professor Catherine Holloway is the PI for the AT2030 programme overall in UCL. The approval makes provision for this study and requires the PhD candidate to adhere to all protocols in the application. A range of traditional and participatory methods are allowed for, including questionnaires, interviews, focus groups, co-creation workshops, and specifically in the case of the PhD, additional stakeholder interviews with Public/ Private/ NGO sectors, policy analysis and one to one interviews with disabled people. This ethical approval is relevant to datasets A, B, C, E, F (all those that relate directly to Freetown).

Following the outbreak of COVID-19, I decided to make the addition of ten virtual interviews with global stakeholders on the research topic (focusing on the issues raised by slum dwellers in Freetown). These global stakeholders were selected as a sub-set of the AT2030 Advisory Board. They were selected based on their expertise, sector representation and diversity. This data was collected under a different ethical consent: "AT2030 – Community Innovation and Assistive Technology in Informal Settlements in Kenya (1106/014), which run from 01/06/19 – 01/10/21, and was amended on 21/06/20 by UCL ethics to incorporate a broader geography. The PI was Professor Catherine Holloway. This approval relates to data collection D only, the 10 virtual, international stakeholders' interviews. The approval required pseudo-anonymisation of the participants, who were interviewed in a personal capacity. Although it might be questioned as to whether such participants might be named as the leads of large global agencies work, this was neither allowable by the ethical approval nor desired, because I sought direct honesty from those with real knowledge, rather than public statements on behalf of organisations. It was also helpful in terms of the concerns raised above relating to my positionality, to keep these conversations anonymous. This enabled honest and unbarred discussion on challenging topics.

The focus of these approvals, sitting, as they both do, under the AT2030 programme inside UCL, means there in synergy in terms of principles of approach.

4.7.1.1 Mitigating the ethical risk factors

Both ethical approvals were considered 'high risk' by UCL, largely in relation to the participant group of disabled people. I firstly note that not all disabled people are 'at risk' or vulnerable. Nevertheless, to mitigate any risk, I did not work with children. Nor did I seek to undertake unusual research methods. I was never alone with participants in the research process (except the virtual global interviews with leading stakeholders). I employed careful data management and took care to avoid breaching the exclusion criteria throughout the programme.

It was also vital to ensure participants knew what they were participating in, and that consent for participation was understood and given freely. For all data sets an information sheet was provided to participants, in their own language in the case of datasets A, B, C, and E, and in English for dataset D. This was verbally explained as part of the AT2030 programme work. Consent forms were signed by all participants.

In terms of accessibility, one vital factor has been consideration as to how accessible the research process was designed to be, and the activities chosen to ensure people with a variety of impairments could participate. AT2030 has accessibility guidelines which were referred to. Accessibility of the process in terms of physically accessible environments, appropriate translation and online accessibility were both necessary and imperfect, especially in the context of urban poverty. For instance, despite every effort undertaken, it was impossible to find sign language interpreters in Sierra Leone, so I was unable to directly interview a deaf participant, though she was able to participate in the wider AT2030 workshops with familiar support. Drawing and photo diaries were used in some of the workshops and this formed part of the corpus of AT2030 SP9 data I referred to in the study.

Careful use of language was also important, including in translation terms. I participated in these discussions as part of the wider AT2030 team and took great care in thinking this through in terms of how I interviewed participants. This actually became a key point of challenge as some of the language I originally selected – the word 'citizenship' – was not understood in the same context when translated into Krio (Freetown's main language) requiring amendment to the topic guide and actually resulting in a considered rethinking of the framing of the evidence, as I go on to discuss.

Given the intention of the work is to find evidence through which to further justice, as part of a wide-reaching programme testing what works on AT access, ethical considerations were paramount, and I was reflective about my intention to be respectful and most importantly to do no harm. Regular discussions with AT2030 team, and both leads for the ethical consents I used, enabled me to explore this reflexively throughout.

4.8 Limitations of the data

While the sample size of the first phase of primary participants (n=16 slum dwellers) could be perceived as small, it is appropriate for a qualitative study on a focused case. This was also only one part of a much larger study, and the data has been cross referenced. Further, testing for different impairment types was not undertaken because it was out of scope, though anecdotally some were easier to manage without access to AT (for instance upper arm amputation was less limiting than lower leg amputation for some), and we know from the RATA that some AT was much cheaper and more available (e.g., spectacles or crutches) than others (wheelchairs). This would be an interesting basis for a future study.

One clear limitation of this study is the inability of the researcher to return to SL between 2019 – 2021, though the local SLURC and FEDURP team remained present in the communities, and partners participated in the later events. This was handled as set out in the COVID-19 pivot.

This work was initially framed around 'citizenship' but initial data indicated it was not a well understood term, despite iterating many approaches, and ultimately trusting the data and a DJ frame fit better.

Further discussion on limitations and further work is included in Chapter 9.

4.9 Exclusions to scope

The scope included reviewing the literature in English around the domains specified but excluded non-English language writing due to the constrains of time and resources – and I do not speak another language well enough to review in non-English. I used grey as well as academic literature wherever possible, but do not claim to have reviewed all possible grey literature – I focused on globally relevant and SL specific work.

One obvious exclusion that is relevant is the publication of the Global Report on AT (GReAT), which was launched after a 12-month delay in May 2022. I have excluded the data in the report itself from the study but included only data and evidence collected to the end of

2021. This was for entirely practical reasons. The data collection had to stop somewhere, and I had to go back to full time work after my writing up period over the winter of 2021/ 2022. There was no chance for me to re-investigate all of the interpretations and data again in light of the GReAT report. However, we are already working on the integration of the findings from this thesis into the work to deliver GReAT as our recent paper shows (Austin and Holloway, 2022). It just was not feasible in the timeframe to revisit 90,000 words in reference to it.

As stated above I am also not a clinician and therefore not qualified to review the implications of this work by impairment on a medical basis. This might be interesting but it was also out of scope given my focus on disability as a social identity and a focus on the Social Model of Disability (Oliver, 2013)

Similarly there is an argument to suggest that care is an important focus for disabled people and as (Piepzna-Samarasinha, 2018) said, it is vital, though organised in historically patriarchal and abusive ways. Overcoming this approach to care and replacing it with a notion of care which is emancipatory has been advocated by some authors (Walker, 2022) yet especially in a country such as SL this is not the current state of play. The global AT agenda also does not relate well to care, and it is hugely contested in the disability literature. I have pulled out occasional issues where they are directly relevant to AT – such as the use of technology by family members to gain health information. However, this is infrequent. To do proper justice to this would be somewhat of another PhD, which I hope someone else has time to undertake as it would be very interesting to read, but unfortunately, it was not something that I had time or resources of methodology to scope in here.

Perhaps related, I have been asked many times why this PhD does not cover issues of accessibility, I think this is because people who are new to disability see this issue first. They often can make tangible disability inclusion or justice through physical barriers, and I have tried to pull out these issues where they are relevant.

4.10 Conclusion to the Methodology Chapter

As the information above shows, the study was carefully designed to deliver the best possible evidence given the challenges, which were considerable. The methodology and methods were adapted, flexibly, to deal with the COVID pandemic, and the resulting data sources have been appropriately correlated to give the most robust and best possible findings, given the circumstance.

What follows is not a perfect study, if such thing exist. It is a robustly designed study which took great care to promote DJ in its methods and approach, albeit constrained considerably by the pandemic.

5 Sierra Leone

5.1 Introduction to the chapter and to Sierra Leone

In this chapter, the background to the detailed national and local study will be presented in the form of an introduction to Sierra Leone (SL) and Freetown, its capital. SL, known colloquially as 'Salone', is a small country in West Africa, bordering Guinea, Liberia and the Atlantic ocean with an area of 72,000 km^2 .The 2015 census (Statistics SL, 2017) found about seven million people resident in the country. Sierra Leone has a tropical climate with hot dry and wet seasons. Only 38% of the population live in urban areas but it is increasing, and up to 75% of the urban population live in informal settlements in the city.

Figure 17: SL in Africa and Freetown in SL. Source: Googlemaps, amended by author.

According to UNDP, 60% of the population of SL are 'poor' and SL is ranked at 180th out of just 186 countries in 2011 (Berghs, 2012). Currently life expectancy at birth is 48, 70% of youth are unemployed or underemployed, 50% of Sierra Leoneans live below the national poverty line, 13% of parliamentarians are women and the adult literacy rate is 41% (UNDP, 2022).

The World Bank's 2021 Macro Outlook for SL (World Bank, 2022b) has 42% of the population living under $1.9/day - the poverty rate adjusted for purchasing power parity (PPP) for international comparison. A further 76% live under the lower middle income level ($3.2/day), and 93% lived under the higher middle income rate, in 2021. In 2022, 90% live under the higher income country poverty level ($6.85/day at 2017 PPP) (World Bank, 2022b)

Figure 18: Two images of Freetown, by Ignacia Ossul

Despite this economic deprivation, Sierra Leone has extensive natural resources; albeit many have been misappropriated throughout colonial rule. It remains a beautiful country with a stunning natural coastline and increasing links to trade in Europe due to its location in the north of the continent. I have been told of a promise of more infrastructure investment from multilateral and international agencies such as the World Bank airport bridge which would cut the time of transfer to the mainland from four hours on the road. This airport link might feel important when you are outside looking in, but most people in Freetown have never been to the airport living, as most do, below the poverty line. There is also a proposal from Freetown City Council (FCC), for a Medellin-style 'teleferico' (cable-car) connection from hillside settlements to the center of the city with hope that similar social spill overs effects will occur as were found in Columbia. These are examples of the discussions around development that are taking place, presently in Freetown and SL, a country that finds itself at the time of writing, in relief from decades of crises.

5.2 Background and recent history in Sierra Leone

5.2.1 Governance and demography

SL is governed through a nationally elected, democratic government, led since independence by a President Head of State and the executive branch of government. Julius Bio has been president since 2018 representing the People's Party. The constitution of SL was adopted in 1991 and updated in 2008 and sets out the declaration of the Republic, principles of state Human Rights of Citizens and the role of the Parliament, Executive and the President. The Parliament consists of 146 seats, 132 directly elected and 14 Chefs from the districts. There are more than twenty ethnic groups with *Temne* and *Medne* being the biggest, and SL itself is divided into chiefdoms (Berghs, 2012).

> "Sierra Leone has 149 chiefdoms, each headed by a Paramount Chief. Generally, these chiefs are male, from a ruling clan, and they rule for life. There are also lower

> levels of chief, all the way down to the village level. Officially chiefs have a very limited set of responsibilities vis-a-is the formal government, such as running local courts to implement by-laws. But in practice, particularly in rural areas, the chieftaincy system is the main authority that many Sierra Leoneans *know and interact with in their daily lives"*
>
> (Walsh and Johnson, 2018, p. 9).

Freetown is the main city in SL and home to just over a million of country's identified population in 2015 Census (Statistics SL, 2016). Freetown was founded in 1792 by freed African American slaves, Jamaicans and poor black Englishmen. In 1808 it became a British colony and in 1896 the rest of the country became a British Protectorate. Independence was fought for and won in 1961 by the Sierra Leone People's Party (SLPP), and although the official language remains English many/ most speak Krio (a variant of Creole with Portuguese) and in the urban settlements as well as the rural areas most people do not understand English.

The majority of the country follows Islam but there is a large Christian minority (although other religions, like Hinduism for example, are not as well tolerated.) Despite a temple at the entrance to Thompson Bay, religious practice is not allowed outside of it, we were told by those than ran it. Additionally, many indigenous religions and secret societies (Berghs, 2012, p. 4) exist. These secret societies – the Poro and the Bondo - act as cultural spaces that serve as political mobilising grounds and the site of powerful gendered interests cultivating and perpetuating traditions and ritual codes, including the use of female genital mutilation (Pemunta and Tabenyang, 2017).

5.2.2 The Civil War

The Civil War between 1991-2002 was bloody and protracted. Following a *'gradual collapse of the state following independence'* (Berghs, 2012) appropriation of wealth and corruption drove a lack of trust between the rich elite (in power) and the poor majority (who lacked the basic provisions of human life). Ultimately the majority took up arms against the state under the Revolutionary United Front of Sierra Leone (RUFSL*)* who engaged in a war with the State (Clotilde, 2017, p. 103). The atrocities lasted more than a decade at the hands of both the national army and the RUFSL. Villages were attacked, occupied and children kidnapped and co-opted into fighting. Many suffered abuse and forced drug and alcohol use, as well as being made to commit acts of violence and witnessing many atrocities. After the war, former child soldiers were promised education and training – but these high hopes were mitigated with a grim reality, with large numbers remaining excluded from education (Betancourt et al., 2008). A former child soldier working in one of the partner organisations for this study mentioned seeing his former war leaders on the street and having to walk on past. Of course, he was not recognised (having been a child at the time of capture) but he recognised the people that had co-opted him. This type of emotional distress is commonplace and overcoming it central to the notion of peace that has been created in SL. As shall be noted, it also goes some way toward explanation for why 'maintaining peace' is a collective act of citizenship, reported often.

Impairment was also used frequently as a weapon of war, with limb amputation being widespread:

> *"This conflict affected thousands of people with villages destroyed, people displaced murdered, mutilated, raped, and forced conscriptions of children into military forces. One of the main atrocities was the fact that amputation was used by all factions…"* (Berghs, 2012, p. 5)

This created a very specific relation to disability in SL, and a differentiation between 'types' of impairment, and their perception of 'cause'. From 2002, *Disarmament, Demobilisation and a Reintegration* programme for combatants (DDF) was introduced, with the *Truth and Reconciliation Commission* in existence to oversee any prosecution through a special court. Disability was a pivotal issue given the large numbers of people who had 'become disabled' (Berghs, 2012) as a result of the war. Berghs (ibid.) writes extensively on the issue of disability and the war, concluding that people had high expectations of the Disability Act (2011) in part because of DDF discussions and promises. But ultimately, as 'stability' or peace looked more certain, international donors moved out of the frame and there were budget cuts and changes in funding priorities. As well as the reliance on aid, the top down process used by the National Government (Bergs argues a colonial legacy itself) created a 'disabling' dependency, meaning that disability (of a certain type) enabled access to specific resources, but those offers themselves rendered individuals beholden to institutionalisation of support and often segregation. Berghs argues that "*while medical care was crucial, one has to ask why an entire group of people were put into special camps based on their impairment counter to all discourses around disability mainstreaming and inclusion"* (ibid., p.193). The *"commodification of the individual medicalised 'tragic victim' identities"* continues to exist (ibid., p.194).

A cursory glance at the national employment statistics for disabled people (1.3%) goes some way to indicate why (Statistics SL, 2016). Freetown hosts at least one informal settlement – HEPPO – occupied exclusively by the families of disabled people, which has risen from these 'camps'. HEPPO have now formed a legal organisation and at the time of writing had resisted occupation using recourse to some of the disability legislation enacted through the 2011 Act. The conflict, the policy decisions taken to resolve peace have shaped the subsequent perception of disability in the country, certainly. Berghs concludes:

> *"the marginalisation and creation of disability was shown on a state, social and individual level, as well as through the inscription of bodily practices and techniques. In a post-conflict society that is moving toward development…people were very aware of these processes and use them, as well as their own cultural resources, to survive"* (ibid., p.199).

Therefore, the construction of disability in Sierra Leone and the social identities, performance and activism around it, is complex and multi-faceted. It would be foolish to try and summarise it in a single defined understanding, but rather this complexity is held in mind throughout this work. Similarly, consideration of Ebola affects the context of this study.

5.2.3 The Ebola Crisis

The 25th known outbreak of Ebola affected Sierra Leone (between 2014 – 2016), alongside neighbouring countries Guinea and Liberia. The scientist that first found Ebola, and went on to run UNAIDS, noted it had already killed more than all other previous epidemics combined by October 2014, claiming the disease seemed out of control and had spilled over into crisis (Farrar and Piot, 2014).

It was not just the primary effects of the direct deaths that affected people in SL, but also the indirect deaths and impairments caused by a lack of access to an overwhelmed health system. Farrar and Piot suggested:

> *"These health system effects will only worsen as the epidemic progresses: West Africa will see much more suffering and many more deaths during childbirth and from malaria, tuberculosis, HIV–AIDS, enteric and respiratory illnesses, diabetes, cancer, cardiovascular disease, and mental health during and after the Ebola epidemic. Indeed, there is a very real danger of a complete breakdown in civic society, as desperate communities understandably lose faith in the established systems"* (Farrar and Piot, 2014).

What remained of an already chronically under-resourced health service in SL, and even Ebola care, was mediated by sababu (connections), cold water (bribes) and (disability and other) stigma; as well as medical need (Walsh and Johnson, 2018, p. 9). While the international community ultimately did respond, the support was late to arrive and then divided along colonialist lines. Sinead Walsh, then Head of Irish Aid and the Embassy in Freetown, recounted arguing strongly for US support for the UK's intervention – this was rejected as they 'don't need help', while US preferred to offer support to Liberia. However, Walsh reported that it took untill December 2015 to get the 700 promised UK Ebola beds open - while MSF opened a unit in 12 days (ibid.). Walsh, wrote with co-author Oliver Johnson who ended up running the Connaught (main) hospital in Freetown as a very young volunteer throughout the crisis after the senior doctor died of Ebola. Their insight reveals much for modern understanding of how a country like SL is managed through powerful interests. Their book summarises some important themes, drawn out here for their salience to this study:

1. *Community engagement is vital and overlooked* and does not get seriously addressed until very late in the crisis. The population 'do not believe in Ebola' and hence do not take precautionary action. Further, community-led responses are not prioritized soon enough. For instance, Community Census book (p.274) helps to record who has died or survived: vital information to the struggle to 'get to zero' transmissions. Chief-led efforts eventually started to work in October 2015 (p.213).
2. *A human rights lens mattered but was not added in the fight against Ebola until mid-way through the crisis*. "It mattered a lot. If we don't start off with a clear acknowledgement of what people are entitled to, simply by virtue of being human, we run the risk of dehumanising them" (ibid., p.275).
3. *Post colonial narratives still played a role* even in such a huge crisis. The UK Government pushed *Save the Children* to run an emergency treatment unit, in Kerry Town, because it had previously taken over a medical charity. However, it really had very little experience. Decisions taken in London to push UK NGOs - explicitly and implicitly - made a big impact (p.259); the clash of (medical) cultures is a huge issue in a crisis, hence it mattered a lot that UK did not have emergency response medical NGOs – like MSF - if the UK were leading the response in SL and determined to use British charities (p.261).

4. *The international community mobilised very slowly*. The failure to declare a more systematic emergency (by WHO) was largely because of the close relationship between WHO country office and the Government which meant that the decision was political rather than medical. *"…countries like SL…. are members of WHOs global governance structure….which is the primary decision making body…The tension arise with Ebola in the spring of 2014 when the public health reality diverged from the political and economic priorities of the affected countries. This happened when the government of Guinea decide that Ebola was bad for business… anxious not to scare away airlines"* (p.39).
5. *When the British arrived (in September 2015) they took control*, often setting up rival structures including the National Ebola Response Center. Though much needed, they often failed to offer leadership to the SL Government or people and "these tensions over power and control including, of course, control of resources, continued and became a major fault line in the response" (p.228). However, "the British provided the gel to bring the burials together" very quickly. Burials were a key issue full of cultural relevance but also highly significant moments for transmission. The UK's creation of the platform through which there could be coordinated action was central to the effectiveness of the UK Ebola response (p.224).
6. *Simple things aided reconstruction* – like a simple excel spreadsheet which was used as a matching process for local people and business (p.203)
7. *Some other services remained relatively well-resourced,* while the country was in crisis. "The HIV service at Connaught, supported by the Global Fund, was run out of a virtually autonomous clinic, with its own pharmacy and medical records system. This approach contributed to the fragmentation of the systems in the hospital. Furthermore, some staff on the HIV programme received additional financial incentives or a separate salary. Health workers would therefore flock toward the donor funded programs leaving critical posts on the general wards unfilled. Thus, while vertical programmes could be an effective way of delivering a targeted health programme, many had an unhelpful distorting effect" (p.29).

This need to focus on locally defined, community adopted, simple and clear action which overcomes both the direct issues and the stigma around it, could be as much applied to access to AT and rehabilitation services as it could to Ebola. It is estimated that more than 100,000 mothers died in childbirth during the crisis, dwarfing those who died from Ebola (Walsh and Johnson, 2018).

Additionally, the stigma remains. A study from Liberia has been published and indicated a low level of satisfaction of healthcare and healthcare access for disabled people during the Ebola outbreak (Carew et al., 2019) and further work by the same team shows the following which is of specific interest to this AT study (Carew et al., 2019; Kett et al., 2021) :

- the mechanisms by which key **public health messages** are shared with communities do not reach disabled people;
- **disabled people trusted** different sources of information to mainstream;
- **targeted 'community responses'** found disabled people to be an afterthought or not thought of at all;
- the level of **access to health and other key services** was low for disabled people;

- **the (lack of) capacity of healthcare workers** and other social services to respond to the wider needs of disabled people was problematic - in Liberia no healthcare workers had received specific training on disability inclusion, for instance. This means that treatment and access for disabled people was ad-hoc, and entirely dependent on the person treating. There is no immediate evidence that this has changed;
- the **role of stigma** attached to disabled people and the resulting impact on inclusion/ exclusion within a community related to the Ebola disease, and otherwise was significant;
- the **indirect consequences** of the epidemic, and response were felt by those most vulnerable; and
- the **transmission of non-health related impacts** (such as access to food, education and livelihoods) was impactful, as shown above.

5.3 Urban informality in SL

According to UN Habitat (UN Habitat, 2015,p.1) informal settlements (IS) are areas where inhabitants have no security of tenure and where the neighbourhood lacks or is cut off from basic utilities, services and infrastructure (for instance water, power, roads). Often housing is self-built, does not comply with quality standards or planning regulations. Often IS are located in hazardous conditions, and inhabitants live in conditions of precarity (ibid., 1). In Sierra Leone up to 75% of the urban population are slum dwellers. The settlements are between 27–61 in number depending on definition that are scattered along the coast and hillside (Walker et al., 2021).

Figure 19 Image of urban informality in Freetown by Ignacia Ossul

As a recent report by SLURC set out, informality is ‘the norm’ in many African cities where urban value chains and services often contain both formal and informal elements (Myers, 2012), and we see that “*even States have become informalized as public officials govern in ways that contravene formal relations, and downsizing public sectors concede an increasing range of governance activities to community organizations*” (Meagher, 2007, p. 406). In Sierra Leone residential or citizenship status or employment might be either inside or outside of the defined legality of the State, but the reality is actually often more ‘blurry’ than straightforward (Schindler, 2014), often switching between informal and formal status.

While informality is often considered in pejorative terms, in Freetown City, National leaders (to a greater or lesser extent) do acknowledge – often positively - the settlements. The idea that informal practices operate in complete isolation from the State is also perhaps unrealistic as (Walker et al., 2021) found - although the implementation of formal regulation and policy in the Freetown settlements was also inconsistently evidenced (ibid.).

In Freetown’s informal settlements, flooding, rock falls, landslides and building collapse are all common and can cause significant economic, infrastructure and property destruction, and the incidence of epidemics, especially of waterborne diseases, is also significant (UN Habitat, 2020). Research into livelihood activities for settlement dwellers in Freetown show that often though these activities – like stone or sand quarrying – might be informal, they make an important contribution to individuals and their families, the settlements they live in, and the economy of the City (SLURC, 2018b). Furthermore, research by SLURC into the impact of informality, living conditions and health, also reveals that the social production of ill-health is aligned with the proliferation of urban overcrowding and prevalent poverty (Macarthy et al., 2018).

Though the settlements are informal this should not imply that there are no governance arrangements in place. In fact, to the contrary, each of the settlements we worked within had a robust structure of representation with elected ‘stakeholders’ – a Chair and Chair Lady (sic) – and representatives of tribal and religious groups, as well as community based organisations. Rules governed what was appropriate in the settlements, as the image below shows. It was taken from the smallest settlement HEPPO showing that organisation of informal governance was present even in the smallest group.

Figure 20 The 'Rules' of the HEPPO settlement

FEDURP was also organised in the mainstream settlements along the lines of other SDI organisations (Tomlinson, 2017) as outlined in Chapter 2. Of particular relevance was their collective work saving towards community improvements, the decision making for which was taken in collective meetings with representatives from the community. At the start of the research this did not include disabled members, but as the empirical chapters reveal this changed through the engagement with the issues. It is helpful to consider the issue of disability in more depth.

5.4 Disability in SL

The background information above is helpful in understanding the context of Freetown; now disability is considered specifically. The Transform Freetown City Plan estimates 93,000 people living with a disability are in the city (Statistics SL, 2016). However, this is very likely to be a significantly large underestimate due to data collection methods.

Sierra Leone signed the UN CRPD on the first day allowable (30 March 2007) and followed with the enactment of the Disability Act in 2011. Regular reports on CRPD progress by the Government of Sierra Leone show significant action on disability rights, and the addition of a standalone pillar in the Medium-Term Development Plan (Government of Sierra Leone, 2019) has also shaped an increasingly positive disability inclusive policy landscape. However, local organisation often highlight the fact that implementation of these rights in practice, and the ability to claim for unfair or unjust outcomes, can be lacking. Nonetheless, disabled people are ‘marginalised in society and the workplace’ (SLURC presentation to AT2030, 2019) with under 2% of the population of disabled people reported as being in employment officially (Statistics SL, 2017).

There is a strong disability sector in SL who have – with the support of some significant international NGOs working on disability – fought and won considerable legal rights. In 2018 Organisation of Persons with Disabilities (OPD), led by the Sierra Leone Union on Disability Issues, SLUDI and supported by the Westminster Foundation for Democracy, published the ‘Persons with Disabilities Agenda’ (PWD Agenda), just before the election in 2018. Their demands included better data, accessibility, access to education, inclusive healthcare and employment rights, but the first demand is very clearly related to civic participation:

> *“We, the disability community of SL, call on political parties to invest in… the inclusion and participation of PWDs in the political process”*(SLUDI, 2018).

The major disability legislation and policy statements to date (2021) in SL do not include explicit mention of AT provision, though this is de facto necessary to meet other commitments around disability inclusion (for instance, inclusive education). The Development Plan 2019–2023 (Government of Sierra Leone, 2019) does mention assistive devices, and the Transform Freetown Strategy (2019–2022) (Freetown City Council, 2019) also refers to creating an ‘enabling environment for persons with disabilities’, which could also be read as such.

5.5 Conclusion

This chapter has set out that the study is conducted within the context of urban poverty and informality, where disability identities are complex, varied, and often considered pejorative. Poverty and precarity are combined with a history of crises and a very specific disability context to set the background conditions for the study.

This type of complexity is rarely considered in the contexts of disability justice or AT provision, which rarely find this a nexus of investigation. Hence why it is interesting to consider with the benefit of deep scope which a PhD study offers.

6 The situation of AT access - availability and definition

6.1 Introduction

In this first empirical chapter, evidence from the investigation is presented in order to address the first research question:

What is the situation of AT access and how should AT be defined?

The section is organised as follows: firstly, section 6.2 restates the definition of AT adopted from the literature (WHO definition) for ease of reference. Secondly, three sub-sections follow summarising the evidence of AT availability at the international (6.3), national (6.4) and local (6.5) levels. The third part of this chapter asks the question 'what is the best definition of AT?' given the data (6.6)? Here, I consider whether the current definition of AT fits the data well, or whether it might be better understood more broadly. This is important because – as shall be shown in the coming chapters – many of the programmes seeking to address AT access rely on these definitions. If what counts as an AT product is proliferating without a strong sense of intention, so might impact be. Therefore, in (6.7) I suggest an understanding of *AT for what?* is pertinent, relating back to the framework set out in Chapter 3 in the discussion. The conclusion to this chapter then paves the way for the next empirical chapter (7) which delves into the evidence of the meaning of disability justice (DJ) thoroughly, before the relationship between the two (AT and DJ) is explored fully in chapter 8.

6.2 The adopted definition of AT

For this study, in common with the Global Report on AT and the AT2030 programme overall, the WHO definition of AT was adopted at the end of the literature review in the framework chapter (3). As summarised in Chapter 2, this definition encompasses both the Assistive Products themselves - referring to any device, equipment or software which supports a person's functioning and independence - and the knowledge, systems and services which sit around those products in order to facilitate their use toward the goal of well-being of the individual (WHO, 2016). The WHO Fact Sheet on AT states:

> *"Assistive technology is an umbrella term covering the systems and services related to the delivery of assistive products and services. Assistive products maintain or improve an individual's functioning and independence, thereby promoting their well-being. Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids are all examples of assistive products." (WHO, 2017)*

The priority assistive products are further refined in the WHO's Assistive Products List (WHO, 2016) as set out in Chapter 2, which is not directly reflected in the definition above but in reality limits the number and type of products further, with a focus on those associated with basic functioning and specific to the support of those with impairments.

This '**priority-products-plus-systems'** definition is also widely adopted in the development sector, including by the major donors and funders. As most of the tools around AT – such as the 'ATA-suite' used in this study (of the Rapid AT Assessment (RATA), Country Capacity

Assessment (ATA-C), Assistive Products List (APL) etc.) all rely on this definition too. Thus, work done in the 'sector' (in so far as there is one on AT) is usually guided by this approach.

For further context, ATscale identifies the rationale for work on AT as follows, in its global AT strategy:

> *"Access to appropriate AT enables people with loss of function, disabilities, non-communicable diseases, and the aging population to participate in education, work, family, and community life. Lack of access to AT has significant consequences for individuals, their families, and the wider society. Without AT, individuals may experience isolation and exclusion from education, the labour market, and civic life. Lack of access to appropriate AT causes poorer health outcomes including premature death, deteriorating mental health, and increased risk of chronic health conditions and secondary complications, all of which lead to a higher burden on health systems. Increasing accessibility and affordability of AT unlocks unrealised economic potential and provides socioeconomic benefit." (ATscale, 2019, p. 3)*

These definitions and intention, taken together, set the tone for AT as being product focused, with services attached, and having a purpose connected to the outcomes of life beyond simple functioning. Relating this purpose of AT more broadly to participation in society is important and noted, but in reality, there is a reliance of the tangibility of products in the operation of the ATA-suite, and the outcomes of life are not defined in any operationally meaningful way. This means that the focus tends to be on the tangible products themselves; a theme which will surface below. This is similar to the International Classification of Functioning discussed in the literature review, a WHO measure of disability, which claims a human-centered social model approach but actually only measures what is tangible (and usually medical).

With this context in mind, below, the evidence on availability of AT, using this definition and these broad assumptions, is presented.

6.3 How available is AT globally and what is being done about it?

6.3.1 The Global Data on AT

The global figures for AT access are most often quoted as one billion people in need, of who only ten percent have access, and rising to two billion in need by 2050 with no predicted alleviation in lack of access (WHO, 2016). These are very proxy estimates reported to me informally (field notes, 2018) by one senior global expert as 'back of an envelope' work, necessary to raise political will.

A data point in itself in this study, was the fact that no participants were able to provide or point to more accurate or robust global figures on AT access beyond this proxy assumption set by WHO. In fact, better data is a core element of the global push towards better AT provision. Preparation for the Global Report on AT (GREAT) has undertaken a prolific data collection exercise which will be published in early summer 2022 but unfortunately is out of scope for this study because of the 12 months delay in the report's publication due to COVID-19. Data collection and analysis stopped for this study at the end of 2021.

Until better data is published, the **900m people in need** figure, is the best available and has been brought into common parlance by WHO, adopted by (ATscale, 2020), AT2030, global donors and was used frequently in the WHO GREAT summits in 2017, 2019, 2021 (WHO). I therefore take this to be the best available evidence of current need, and taken together with the trend expectation **WHO suggest, we can assume that need will double to 2 billion people by 2050, with no predicted alleviation in lack of access**, due largely to an ageing population, if interventions are not stepped up. As one international expert stated – this renders the problem of AT access 'urgent and pressing' (D-I-01).

The WHO GATE (Global AT Exchange) Initiative also devised a **Priority Assistive Products List** (WHO, 2016) which sets out – after much global debate – what AT is (as outlined above), and which fifty products are the most necessary to address access to AT. It states:

> *"Priority Assistive products are those products that are highly needed and absolutely necessary to maintain or improve an individuals functioning and which need to be available at a price the community/state can afford"* (Ibid.).

Of these fifty priority products WHO, ATscale, AT2030 and the global donors working on AT (USAID, NORAD and FCDO) have prioritised five: wheelchairs, hearing aids, prosthetics (and orthotics), eyeglasses and digital devices. These products were prioritised by unanimous decision of the Forming Committee [5] of ATscale in Washington DC in early 2018 (from my notes attending the US meeting, 2018).

Most recently, AT2030 & ATscale have jointly produced 'Product Narratives' on each of the priority AT products setting out the 'state of the market' and core objectives to increase availability and affordability of each of the five prioritised assistive products. The product narratives were considered by the international stakeholders I interviewed to be a key requirement of creating AT access. It is helpful then to understand what these market narratives say, and how they are presented. The table below (Table 6) provides a summary of these product narratives, produced between 2019 – 2021 by CHAI, overseen by GDI Hub, alongside the issues of relevance to this study which are drawn out as part of the analysis.

Table 6: Product narratives and relevance to study.

Product Narrative	**Products focused on**	**Key Recommendations /Strategic Objectives for Global Action**	**Relevance to the Study**
Wheelchair PN, 2019	Wheelchairs (and associated services).	• Build and stimulate demand through the integration of wheelchair services, including procurement & provision, into healthcare systems	Globally more than 75m people need a wheelchair but 85-95% do not have access. While 90% in need in higher income countries

---

[5] The Forming Committee of ATscale met from 2018 – 2019, and comprised of China Disabled Persons' Federation, Clinton Health Access Initiative, Global Disability Innovation Hub, Government of Kenya, International Disability Alliance, Norwegian Agency for Development Cooperation, Office of the UN Secretary-Generals Special Envoy on Health, UK Foreign, Commonwealth and Development Office, UNICEF, US Agency for International Development, and WHO. I was the GDI Hub representative on this Committee.

		• Pool resources to catalyse increases in funded demand and to limit fragmentation in the market • Strengthen procurement via adoption of specifications and standards, improved tendering and increased market information • Identify and support cost-effective supply systems	are estimated to have access, this is estimated to be close to only 5% in LMICs. The primary global manufacturers do not target LMICs. Procurement is proliferated and quality varies greatly. This aligns with the data from Sierra Leone.
Hearing Aid PN, 2019	Hearing aids (in the context of Ear and Hearing Care programmes)	• Strengthen global policy guidance around service delivery standards, product selection and product quality; • Support LMIC governments to strengthen hearing aid provision including demand generation and investment in service delivery capacity, government purchasing and procurement support; • Engage the private sector to expand delivery of affordable, quality hearing aids and related services; • Work with suppliers to enter LMIC markets with affordable, quality hearing aids; • Spur innovation to support simplified provision models and introduction of optimal products.	Around 466m people globally have disabling hearing loss and this is expected to double. Estimated coverage with Hearing Aids in LMIC 3%. Five suppliers control 90% market. A high cost, combined with a lack of quality and poor follow up services mean demand is low and poorly understood. Our data did not reveal any access to hearing aids in SL.

Eyeglasses PN, 2020	Eyeglasses (and associated services)	• Mobilise key stakeholders, including donors, multilaterals, NGO implementers, and the private sector, around reliable data and scalable proven models to accelerate efforts against vision impairment caused by refractive errors. • Strengthen global policy guidance around service delivery standards for low-resource settings to accelerate the adoption of innovative models, devices, and products that support a simplified service delivery. • Support governments to develop comprehensive eye care plans integrating validated models of vision screening and provision within the public health system, and facilitate scale-up of those models • Engage the private sector to expand delivery of affordable, quality eyeglasses and related services in LMICs. • Build and drive awareness and consumer demand for eyeglasses.	It is estimated that at least a billion people have a visual impairment that is uncorrected or could have been prevented. Correcting refractive error with eyeglasses is a simple intervention. Markets focus on high value global north, with limited public investment and stigma. In Sierra Leone spectacles were the most accessed AT and often accessed through the informal market.
Prosthetics PN, 2020	Prosthetic devices - upper and lower limb (and associated services)	• Develop foundational datasets to inform the investment case for prosthetic services and guide the development of standards • Support countries to define appropriate policies and invest in the	Globally it is estimated that 1.5m people undergo amputations every year and need access to prosthetic devices which can improve quality of life and improve health

		key requirements of a functioning prosthetic provisioning system • Accelerate market validation and adoption of innovative technologies that can simplify, decentralise, and lower the cost of prosthetic service provision. • Accelerate the uptake of affordable, quality prosthetic components by increasing market transparency to empower buyers to make value-based purchasing decisions. • Strengthen regional supply mechanisms to increase affordability and availability of quality prosthetic components.	outcomes, with only 5-15% having access. Rapid innovation in the sector – including though digital fabrication – is opening up opportunity to reduce expensive fitting and production costs of traditional methods. Prosthetics were expensive and hard to obtain in SL, but need is complex and considerable due to the nature and number of amputations as a weapon of the Civil War.
Digital PN, 2021	• Smartphones • Accessible Devices • Accessible Platforms • Screen readers • Augmented and Alternative Communication Devices (AAC) • Accessible Software • Applications • Accessible Content	• Develop and adopt policies, including legislation, regulations, minimum product standards, and guidelines to support accessibility and uptake of digital AT at global and country levels. • Support LMIC governments to increase awareness of digital AT by including digital AT products, such as smartphones and AAC devices, on national assistive product lists. • Support innovating financing schemes or negotiate pricing agreements to reduce the cost of digital AT to end users.	Disabled people have less access to smart phones in LMICs and data costs can be high. Digital devices are not always available either, and often software is not accessible, or skills training is required. Some participants had access to mobile phones in SL but not all and many were Feature not Smart Phones. No other devices were noted.

		• Increase availability of training programmes for users, suppliers, and service providers on the importance of digital AT and digital literacy skills.	

What this summary reveals across the global markets for priority AT Products (AP) is as interesting as how it is presented in these product narratives.

Taking the first point first, there is a broad commonality of recommendations across all AP. These relate to the strategic interventions actors can take– often system strengthening support - such as policy development, data collection, procurement support, and better information. This is not surprising due to the commonly understood market failures in the sector (as reported in Chapter 2) relating to these same elements. However, product narratives are largely addressed at multilaterals, and global donors as well as, to a lesser degree perhaps, the Governments who will seek support to implement them. Thus, it is perhaps to be expected that addressing imperfect information, the principal-agent split (where the purchaser of a good and the user of it are different), and procurement practices are paramount among the solutions which make their way into the recommendations. In addition to influencing those designing services, PNs are also intended to signal to the (private) suppliers which markets are emerging – e.g., fruitful to consider entering.

Crucially, the PN approach builds on what has worked on the reduction in price and increase in availability of vaccines and essential medicines referred to this as ‘market-shaping’. The product narratives do touch on the issue of the differential nature of AP from previous global healthcare product intervention - though do not go into any detail; to be fair in part because this has not been tested yet. However, the idea of market shaping for AT as a concept, is discussed in the GREAT summit paper (Savage et al., 2019), which identified that while products such as bed nets or vaccines are standard, AP are often specific to the person, need to be provided many times across a lifetime, and also require fitting and other training support and use of services. Hence the *product* is not the only element affecting the efficacy of the intervention, while the market-shaping approach is more focused on products than services, historically. While the nature of the service provision is recognised as important in the product narratives it is much harder to measure tangibly or to quantify, as we saw with the definition of AT.

Similarly, some AT2030 programme interventions address service provision; For instance, supporting ‘task shifting’ interventions designed to support moving tasks which can be done by a lay person to the purvey of community health workers, such as screening. This helps to increase access to screening, and relieves the burden on the very few trained clinicians in low income countries. Training modules for community health workers and *one-stop-shop* pilots (bringing all activity together in one location) are also interventions that are intended to address service provision, but there is no global measurement of the ‘services’ gap in AT access by AT2030. Hence what the product narratives do not say – and arguably could never say – is probably as important as what they do say about AT access. Nevertheless, they are an important evidence point in the picture. This is a discussion that will be returned to as we consider the 'for what' of AT access, but first the global experts views are presented.

6.3.2 Evidence on the initiatives addressing AT access globally

The analysis of Data D - International Expert Stakeholder interviews - illustrates and enhances these themes set out above. Responses are anonymised as candidacy was preferred over accountability, and was a requirement of the ethical approval.

Many participants, for instance, D-7, mentioned how pressing AT access is globally as a key development issue, and how much it has increased in prominence over recent years:

> *"AT can provide better access to education, jobs, participation…AT is an enabler, we would like to see that everyone had access…We talk about giving people AT access so they can fulfil their human rights. We say it, but not in these words. AT fits into several sets of beliefs, and it is not in a single framework to solve. What I'm really looking forward to is the Global Report."* (D-7).

It is worth noting that AT is not connected into a single approach, in this quote above, and that was a common response and something we shall return to. However, to reemphasise its importance first, another interviewee, D-6, makes a strong case for AT as a Human Rights concern:

> *"AT removes barriers to people being part of society; It's not the only barrier, and sometimes it's not the most important barrier; but it's a significant barrier….. AT is a mediator, but also as a moderator of the attainment of the SDG's and the SDG's are what underlies Human Rights. Putting the first last and leaving no one behind is all wonderful rhetoric, but AT is where the rubber hits the road."* (D-6)

This quote also highlights that AT is a mediator and moderator of a boarder aim which is harder to quantify. AT is not the end goal in itself of the change we want to see in the world, and this was a common presentation. Most often, when reference was made to this broader goal, it was as set out in the CRPD and SDGs and sometimes reference was made to a 'twin track' approach (e.g., the targeted approach plus mainstreaming set out in the UN disability strategy). AT was viewed as a core element of disability inclusion:

> *"One way (of addressing inequality for disabled people) is ensuring that we, through our programming, start integrating persons with disabilities as the target population, and build a greater understanding of their specific needs. But there's a range of different services and products to (ensure) access to a range of different services and products needed, just to be living as 'normal' a life as possible (however that is defined) - I'm thinking that AT, it is such a such a critical component and there's such a tremendous role for Health Ministries to showing leadership and ensure that they have the systems in place to adequately deliver those services".* (D-1)

There was consensus then – as one would expect from a group of global experts working on AT – that AT access was problematic and requiring of priority action. There was also broad agreement that this effort for AT access, should be seen as part of a broader set of aims.

However, when asked about specific goals and targets on AT access, there were none in common, beyond the programme level collection of outcomes necessarily recorded for AT2030 which some parties were reporting on. This reference to project targets was to be expected since they mostly worked on them together. However, beyond project level goals and targets, AT progress was difficult to measure. It was also often pointed out that specific objectives and measures need to be framed in the context of a national level, as D-3 said:

> *"Global programmes are in a silo, so its up to us, global policy makers and teams – its our collective responsibility, to make sure we join the dots…One danger is that people working at a global level haven't worked at country level and don't know how overwhelming it is when there is so much stuff coming down to countries…Recently (due to covid) we haven't been able to fly around the world with our superhero outfits on and our colonial model of aid and instead we have been empowering local teams."* (D-3)

The reference here to global policy making and the connection to able-nationalism is not lost for AT at all. As highlighted in the literature review the notion of donors *knowing what's best* is commonplace and AT does not escape this trend. Another expert – himself an AT user hailing from Africa- noted this is part of a broader trend:

> *Interviewer: Do you think global work on AT currently fits within a particular set of beliefs or global political framework?*
>
> *"It goes beyond AT, it comes from the history of the Global North always prescribing things to the Global South – trying to feed the Global South from the crumbs that fall off their table and this transfers to work on poverty and disability Also, it [the Global North] interferes and creates more disabled people (through wars) and also the political system is interwoven with the UN programmes. Only big global donors can pour money into R&D."* (D-4)

This reflection also offers a perspective on the ways in which the Global North intervention is not always helpful, and can be charged with other priorities as the literature review section on the commodification of aid revealed.

Another key issue raised by global experts was in relation to the disconnect between the AT sector and the disability rights movement, globally, as one participant (an AT leader) noted:

> *"The Disability Rights movement is a largely a movement of the northern people – these people have all the AT they need, so they don't understand the people of the developing world".* (D-10)

While this may be true, I do not believe it is that simple. There are other reasons the disability rights movement is disconnected from the AT movement – due to is medical approach, connection to health agencies, and the fact AT is framed without a strong connection to disability rights sometimes.

Suffice to say AT is lacking and there is an international consensus that we should do more; interventions are increasing and increasingly well-funded. However, despite the desire for more impact, no common framework through which to address AT access, on an operational level, was revealed in the evidence collected.

Now I will look at the national data.

6.4 National evidence - how available is AT in Sierra Leone and what is being done about it?

6.4.1 National data

At the very end of the data collection period for this research, on 26th November 2021, the Government of Sierra Leone held a conference in Bo, a regional City, to mark the launch of a new **SL Assistive Technology Policy and Strategic Plan**, and a **SL Priority Assistive Products List** designed especially. This follows the work undertaken by AT2030 since 2018 including a Country Capacity Assessment (CCA) on AT for Sierra Leone using the WHO's assistive technology capacity assessment (ATA-C) supported by CHAI; a Rapid Assessment of Assistive Technology need (rATA) and informal markets study led by DPU. The ATA-C and rATA are part of the WHO toolkit to advance data collection on AT, a full description can be found on the WHO website (World Health Organization, 2021)and relevant details are summarised in Table 7. The WHO ATA-C tool was privileged to (virtually) speak at the launch of these two new documents, which were promoted alongside a newly established budget line for AT in Sierra Leone and the new working group on AT have been brought forward under AT2030, despite the COVID-19 pandemic. I believe the event shows evidence of significant commitment and progress by the Government.

Table 7: Overview of ATA-C and rATA tools.

The assistive technology capacity assessment (ATA-C)	The rapid assistive technology assessment (rATA)
• A system-level tool • Evaluates a country's capacity to finance, regulate, procure and provide assistive technology. • Can also be used to bring diverse stakeholders together and build momentum for action.	• A population-based household survey that measures the need, demand, and barriers to accessing assistive technology. • Can be used alone, incorporated into broader household surveys or in national censuses. • Intended to be implemented by a team of trained surveyors.

None of the published reports, conference proceedings, or evidence gathered presents a figure for the need or access of AT nationally in Sierra Leone, beyond the international estimates. In order to establish that information, the RATA or a similar household survey would need to be repeated country-wide, or in a region with a statistically significant sample size (to date it has only been done at settlement level), as is being done in many countries in time for the World Report on AT being published mid-2022. Rather, what can be gleaned from the research that has been undertaken on AT in Sierra Leone in the last years is that the national absence of AT is unlikely to be less than the international trend, the quality of the provision priorities are shaped around the need for systems support, the prioritisation of products within locally accessible markets, and the connection between products and services – as the product narrative set out.

Further detail is now explored below.

6.4.2 National priority actions – focus on systems change

The initial **Country Capacity Assessment** conducted by CHAI for SL's Ministry of Health in 2019 indicated national provision of AT did not have the coverage required to meet the need. This was reported in our paper (Austin et al., 2021a) which synthesised the CCA data. At that point in time the GoSL was relying on population and household survey data estimating fewer than 100,000 people might be persons with disabilities who may need AT; a figure they had already begun to question themselves in discussions of the National Disability Commission attended during the 2018 scoping visit (field notes, early 2018). At the time of the CCA there was also no register of AT procurement or provision across governmental services. Though the Government did know it provided some 500 wheelchairs per year; it knew no more. From my professional experience I can say the GoSL have this lack of evidence (about *who* is purchasing *how many* or *what* for *which price*) in common with most Governments, including the UK NHS, who have just commissioned GDI Hub to analyse this gap.

Anecdotally, from observation between 2018-2019, the AT 'market' in SL operates in a proliferated way, and in fact is more of a market of markets where the formal sector provision is a mixture of (few) state owned and run rehabilitation facilities, with very limited resources, focusing on more clinical products like prosthetics. This is coupled with some provision through hospitals, which is supposed to be free for disabled people, but usually is not, but is supported by some charitable donations often of lower quality products. There are formal and informal shops and markets, which sell AT, often at a price that is still unaffordable, and there are informal street sellers of simpler products like glasses. The withdrawal of key international NGOs, such as Humanity and Inclusion, from direct provision (in favour of the government capacity building) has been a significant change in the market. As this chapter shows most people that need AT do not have it so we can conclude the market situation is not optimal. Though there was some evidence of local manufacture (for instance Mobility Salone in Bo) still it was clear that trained personnel were lacking (with only 17 physiotherapists in the country), and there was no proper account yet taken of quality control, strategic procurement opportunities, or cost per unit distributed (Austin et al., 2021a).

In part to address this lack of functioning, evidence and coordination, a **National Disability and AT Technical Working Group** was established to oversee a new National AT approach, established during COVID-19; it met virtually supported by CHAI under AT2030. While I participated in these discussions in a work capacity, I observed that it was this group that drove forward much policy change in 2020-2021, and precipitated the event.

The informal (unregulated) provision of AT, through informal shops, street sellers, informal markets, second-hand shops, or roving sales people, is a commonplace way to procure goods and services in SL, especially for urban poor people. Medicines are also procured through this route with much associated risk. In fact, one participant in this study, reported an AT2030 participant passed away during the research, apparently due to informally purchasing and taking the wrong drugs (E-02). A specific study commissioned by GDI and undertaken by DPU investigated the provision of AT via the informal market in SL. The **Informal Market Study** found that 30.8% of the assistive products identified through the assessment in Thompson Bay and Dworzark settlement were procured from the informal sector, with a further 3.1% being self or home made (Walker and Tebbutt, 2022). This idea of informal provision was supported by the data from the community interviews too, and it was clear this was still too costly for many:

> *"The government is not helping us. In the past, at the place at Aberdeen (informal shop) the AT was not much expensive, but now it is very much expensive to buy the AT products."* (A-D-01)

The AT Policy and Plan for SL 2021 – 2025 (Ministry of Helath and Sanitation, 2021) was developed in part using these studies as data, and as mentioned above, was launched by GoSL in November 2021. The policies are intended to guide the Government's priorities, and in particular the Ministry of Health and Sanitation, and other relevant ministries, alongside NGOs, DPOs, development partners and other actors in improving access to AT in the country. The commitments comprise of five policy statements with eight strategic objectives encompassing 40 activities ranging from raising resources, to improving coordination and monitoring. Acknowledging the lack of coordinated action on AT previously (as found by the Country Capacity Assessment in 2019), the new policy provides an important and missing (still, in most countries) framework which aims to bring together AT provision, rehabilitation services and health care at the primary, secondary and tertiary level. This intervention largely follows the global approach set out by WHO, which it would be naïve to assume was not in part motivated by the hopes of attracting Donor funding towards its delivery.

The purpose of the **Priority Assistive Products List for Sierra Leone** (Ministry of Health and Sanitation, 2021) then, is to help "*improve access to appropriate, quality Assistive Technology (AT) products at an affordable price that will help enhance functioning and independence of those who need them while facilitating their participation and integration in society"* . The policy identifies 70 Priority AT Products as priorities for Sierra Leone and in doing so seeks to contribute to addressing gaps related to AT procurement and service provision by the MoH. Seventy is a lot of products, but at least identifying these can be a starting point and market signaller indicating where innovation and or market shaping activity (such as pooled procurement with other countries) may occur. The document also highlights some of the challenges in the markets for these products in Sierra Leone including the high unmet demand for AT, high out-of-pocket burden to the individual in accessing AT, poor resource allocation to the rehabilitation centers, and a market which is driven by charity and donations rather than need and strategic interpretation. To alleviate those challenges, the report makes strong recommendations for local manufacturing of Assistive Products and allied services, allocation of sufficient funds for the AT program within the National Rehabilitation Center (NRC) which has a number of locations across the country, the development of a Management Information System (MIS) to capture delivery of assistive technology products (to the beneficiaries by the Government or Donors), building human resource capacity in rehabilitation and more.

A side note on complexity and local production

As a personal reflection from my wider practice: it is not uncommon for a Global South Government to suggest local production (sometimes unhelpfully aligned to local employment of disabled people) as a solution to AT access. In the 35 countries AT2030 works in, I have yet to see these issues easily solved in one move, because the complexity of building local economies, employing disabled people and providing AT each bring their own tricky challenges, and they do not require the same actions, therefore are not necessarily solvable in easy combination. For instance: local production of AT in a large East African country is run by an NGO set up by the Government and staffed by disabled people. It does produce AT products, but they are more expensive, slower in production (which is manual) and therefore of a resulting lower quality than the best imported versions so there are many complex choices here resulting in long term or short term gains. Ultimately the NGO does not service more AT to the disabled people of the country, but the minister ticks a lot of boxes. There are some signs it is possible to do better, but it is not necessarily likely. This is not an argument for blanket imports, but an argument for clarity of purpose, prioritisation and honest discussion about complex issues.

Nonetheless, in SL the publication of these policies represents a seismic shift in ambition toward growing system capacity on AT in SL - from identifying need, right through to the delivery of quality AT services in the country. It will certainly lead to improvement in assistive technology access and user satisfaction if, vitally, it is well implemented.

One disabled slum dweller from Dwozark interviewed for this research throughout, was supported to travel to attend the launch in Dohas Bo and articulated his hope for this work perfectly (by What's App after the event):

> *"The content of the policy is truly favouring people with disabilities in what we have been yearning for far too long. Going forward we would be very happy-go-lucky if the document doesn't remain on the shelf, but its contents are translated into practical reality."* (A-D-02)

The Government can be applauded for its considerable efforts, especially at a time of global crisis. Yet the concerns of this disabled slum dweller are rooted in evidence of previous policies which have not been implemented. There were many examples of this in the evidence, in relation to free education and free health for disabled people - both of which are provided for under the Disability Act. The reality often looks different:

> *"You go to the hospital, and you will have to buy everything...when the money finish they will discharge you whether you get better or not … If you have the medicine but not the needle, they will not attend to you."* (A-D-02)

This exemplified the comments by many which will be returned to in later chapters, that provision in law did not equal provision in practice where additional costs, discrimination, bribes (cold water) or sababu (connections) were needed to get to the front on long queues.

So, the publication of the AT policies is not the end of the story – far from it. In addition to implementation, there are also some aspects which are harder for the Government to address, or at least where their policies go less far, such as the operation of the informal market. However, it still must be stated that things are moving forward at some pace at a national level in SL.

Now I turn to the local level.

6.5 Local evidence - how available is AT to slum dwellers in Freetown and what is being done about it?

6.5.1 Introduction to the local data

For the AT2030 project three Rapid AT Assessment (RATA) surveys were undertaken in the three informal settlements in Freetown this study focuses on, in September 2019 (Dworzark and Thompson Bay) and January 2020 (HEPPO settlement). This evidence is investigated and presented below, enhanced by individual interviews with disabled slum dwellers conducted in 2019 and 2021 (virtually).

6.5.2 RATA findings – Dworzark, Thompson Bay and HEPPO

As part of the AT2030 project, a RATA survey was undertaken by the SP9 project team trialling a (then) newly developed WHO tool (Ossul-Vemehren et al., 2022) in three informal settlements in Freetown. The aim was to establish need, availability and quality of AT available to the slum dwellers via a house-to-house survey. The RATA had been developed by WHO primarily to focus on data collection around access to assistive products, rather than the whole AT ecosystem (referring back to the point made earlier on what it is possible to count). The data is collected using mobile devices and while it has now been used in many countries this was one of the first trials, using a pilot version of the tool. Certainly, it was the first in the informal context.

The AT2030 DPU team ultimately decided to re-make a free-to-use version of the WHO app with support from the Nossal Institute and ULC Engineering, to enable easier data collection by the local research team who were trained slum dwellers themselves; the official app was hard to adjust to local context and restricted access behind a paywall. As an aside, this pilot enabled the GDI Hub to report back some of the learnings to WHO at a global stakeholder meeting in 2020, which informed the final RATA tool development for WHO, so was a valuable trial in and of itself.

As explained in chapters 4 and 5, the settlements of Thompson Bay and Dowrzark were self-selected by the Federation of the Urban and Rural Poor (FEDURP) communities and their leaders for work on the AT2030 programme. They are both ‘mainstream’ settlements of urban poor people, meaning that they have mixed membership, including mostly non-disabled, but some disabled people. Dworzark is a hillside settlement, and larger and Thompson Bay is a smaller, costal settlement. Neither had any mechanism for the organisation of disabled people.

The HEPPO settlement is different in that it is a community that was constructed by disabled people for themselves and their families. HEPPO stands for Help Empower Polio Persons Organisation and the group is made up of households of disabled people who came together to squat the land next to the Prison in Pademba Road in 2000. HEPPO has registered itself as a Disabled Persons Organisation (DPO) and it has had some success in lobbying against eviction as we shall see in later discussion. The table below summarises the findings of the RATA survey (Ossul-Vemehren et al., 2022)

RATA key findings	**Dworzark and Thompson Bay**	**HEPPO**
Population	N=2076 individuals surveyed with a young demographic with 71% of respondents under	N=134 individuals surveyed across 54 households each with 1-14 members. 59% male.

	29 and slightly more female respondents.	
Disability (as defined by self-reported figures using the cut off as 'some difficulty' or 'a lot of difficulty' or 'cannot do at all' with regard to the activities of daily life (seeing, walking, concentrating etc)	21% of the respondents self -reported in a way which would classify them as disabled people by this tool's methodology.	37% total population (of which 48% adults) reported in a way which would classify them as disabled people by this tool.
Barriers	Seeing and mobility were the most commonly report issues.	Mobility and self care (eg washing and bathing) were most reported issues
AP coverage	Low. 15% of the population that has a difficulty has at least one device, women and girls have less (13%) and men and boys more (18%); Dwozark (18%) has better coverage than TB (9%)	High. 71% (35 people 41 products)) who needed AP had access to at least one device
Type of AP	81% of devices (52 pairs) were spectacles. Remaining devices were walking aids (6), manual wheelchairs (3), orthotics (1).	Most common AP was Wheelchairs (19 of 41 AP devices found), with 6 tricycles and the remaining various types of crutches.
Where did AP come from?	Most common was to purchase the spectacles from the informal market (31%) followed by government hospital (28%).	Wheelchairs and they mostly came from NGO (45%) or were purchased from the informal sector (16%)
Satisfaction with devices	Respondents were generally satisfied with their AP.	69% said 'moderately' helpful in everyday activities.

Source: Adapted from the FACTSHEET ON AT PROVIDED TO PARTICIPANTS at the AT CONFERENCE IN SL ON 26.01.21 (full results in Ossul-Vemehren, 2022)

As the table above shows, for slum dwellers in the mainstream settlements in Freetown (Dworzark and Thompson Bay) 21% of adults self-classified in a way that met the cut off point for 'disability' and their access was broadly in line with the international assumptions. Up to 15% of the population had access, but most of this access (81%; 52 pairs) was to eyeglasses purchased most often (31%) from the informal market. Women and girls had less access (13%) than men and boys (18%). In the autonomously run settlement led by disabled people and their families (HEPPO), 48% of adults self-classified in a way that met the cut off point for 'disability' and 71% of those who needed assistive products had access to at least one device. Here the most common were wheelchairs (19 of 41 AP devices found) and tricycles (6); most commonly these came from the NGO sector (45%).

As reported in our paper (Austin et al., 2021a) affordability is the main reason people provided, for not having access to AT, alongside not being aware of what products they needed, or them not being available. This lack of knowledge about what is needed, is not insignificant. For instance, although there were only a few, all of the blind people surveyed said they needed eye-glasses, whereas perhaps a white cane would have been of more use.

Now, it can be helpful to compare this data to the first-hand accounts of participants collected through Data A & E for this study. Here, in the next section, we see a similar pattern described.

6.5.3 First-hand accounts of AT access for disabled slum dwellers

AT access was incredibly limited to slum-dwellers in the mainstream settlements as the data shows. If one deducts the eyeglasses, almost all slum dwellers that needed AT did not have it or were using sub-standard products, such as this prosthetics user who was able to get his device through Humanity and Inclusion (HI) when they still operated in Sierra Leone:

> *"I got my leg in 2007, I think it came from France."* (A-D-05)

That participant was still walking around on the same leg at our last discussion at the end of 2021, and every day it is probably exacerbating his impairment due to ill-fitting and its age. Rubbing and ill-fitting prosthetics and wheelchairs can cause sores which can ultimately cause death in a short number of years so this is not a small or side concern.

Where AT was available to participants, the data showed it was expensive and had been privately purchased, as one woman recounted:

> *"My parents bought me a crutch . . . but was very expensive (150,000 leones, about £13) . . . and it has a snapped armrest . . . it costs about 30,000 Leones (£2.50) to replace the rubber feet . . . .Without my crutches, I couldn't go anywhere."*
>
> (A-TB-01)

But most people in the mainstream settlements did not have access at all. This man had the only wheelchair I saw, and the wheels did not go around, it did not wheel. It had been found many years earlier abandoned, and though the chair did not move or function, it was still considered valuable and carried (along with its occupant) to all AT2030 meetings. He said:

> "In the morning my son moves me from my bed to outside my home [shack structure] under the tree, sitting in the [broken, static] wheelchair. I am more comfortable sitting there because it has a lot of wind blowing and shade, so it helps me a lot. After 7:00 pm, my son takes me back into my bedroom." (A-TB-04)

It was also common for slum dwellers to refer to the hope of AT, which they often heard about in the media, but it did not materialise:

> *"You hear these things like wheelchairs have arrived for the disabled (sic)'... but when you go to the office . . . they never say when they are going to distribute them*." (A-TB-08)

HEPPO had much better access, as the data above shows. One international expert commented:

> *"HEPPO …with a high coverage of AT…the case is important but also unique. Most people acquired their impairment (Polio) early as it tends to affect children under 5, and one assumption is people have more time to understand their condition and access something. The other alternative is that by living together they share information collectively, get AT, and raise awareness of the AT they need.*
>
> *They have had the First lady visit them!"* (D-05)

This quote identifies a key question of whether AT access was aided by collective advocacy and information sharing? This is important and we shall return to discuss it in the later sections where we will see that this shared approach is considered valuable. Suffice to say for this chapter, it can be assumed that for most disabled people in Sierra Leone, AT access was not provided for. Even HEPPO claimed for more than they had.

I cannot close without a word on the considerable impact this has on what AT users were able to do, though this is discussed later. One participant summarised that a lack of AT rendered her life incredibly difficult to derive meaning from:

> *"I have to stay home most of the time . . . you can't use the public toilets; you can't walk around, and no space is easy."* (A-TB-01)

The data on AT access has now been considered internationally, nationally, and locally and it has been shown that this is considerably lacking, with increasing momentum and programmes to address access at least at global and national level. Given the limited resources and need to direct them well, it is necessary to understand if the definition of AT currently fits the data and is useful to this goal.

6.6 How should AT be defined, given this evidence?

6.6.1 Challenges to the settled definition of AT

As highlighted above, stakeholders interviewed followed the priority-products-plus-services view of AT, led by the WHO. It was necessary to first understand something of the access to, type and use of AT, in context, before now coming back to a more detailed analysis of how AT is defined, in order that a more critical view can be offered.

The following section now highlights some of the thematic areas arising from the data which transgress this assumption of AT definition. It includes evidence from interviews, event transcripts and field notes kept between 2018 – 2021, to draw out salient themes. The themes are set out organically first, and then considered in relation to the DJ framework.

6.6.1.1 AT viewed as part of a broader 'accessibility' agenda

The first challenge to the settled definition of AT came from those who represent the global disability rights movements among international experts. They, in particular but not exclusively, tended to see AT as part of a wider story of the access adjustments, which should be made to enable the full participation of disabled people in society, following the social model of disability I discussed in Chapter 2. Similar to initiatives to improve the inclusive design of the built environment or the reasonable accommodation to working practices, AT in this understanding should be viewed as an enabling factor, rather than a 'thing' by itself. The following quote summarised this view:

> *"I think AT would be one of the many possible reasonable accommodations enshrined in the Convention on the rights of Persons with Disabilities…I would describe it as 'technology designed to bring down barriers that would prevent people from accessing their human rights"* (D-08)

Implicit in this view, is the fact that the disability rights movement has for a long time tried to move away from the idea of 'fixing' the individual, rejecting of the Medical Model of Disability described in Chapter 2. Hence the presentation of AT as a product which can 'solve' disability is incredibly problematic in that context.

For this reason, following the rationale above, AT has often found itself far from the top of the agenda for global disability leaders. This idea of AT, beyond a product and as part of a wider construction of 'reasonable adjustment' would suggest a stronger connection of AT programmes to inclusion outcomes is needed to be drawn out. WHO are unlikely to be the right leaders of this type of approach because they are health focused, not disability specialists, and do not represent the disability community.

On the other hand, though, this is not a very specific definition of AT, and could really be applied to many interventions; it does not recognise the specifics of the services and practical support required (if technology is read as a 'thing' not a 'service plus a thing'). Finally, this to me reads more as a contribution to a high-level objective of AT not really a definition of AT itself, building on the historical definitions. However, from this I take the need to connect better to the social model of disability and to question the focus on traditional products. Let's consider that now.

6.6.1.2 What is a Priority Product?

A second problem with the WHO definition, is that the APL took several years to be agreed and was not without considerable contestation in the process, as one of the participants (D-I-05) noted. It is also currently being revised again in part to reflect the evolution of technology. APL version 1 has had some notable exceptions to what counts as assistance which have become more pronounced as shifts and changes of tech take place. The following problematics have developed from fieldnotes and participation in discussions on prioritisation of the global products with ATscale (2018), and the three GREAT summits (2017, 2019, 2021):

- **'Non-tech' / tech assistance is blurring**: Guide dogs, human sign language interpreters, and personal assistants, while not technology, were strongly argued for by some constituents when APL 1 was being constituted; all were excluded, but increasingly the dividing line becomes somewhat messy or arbitrary. For instance, as tech-augmented solutions take over human sign language interpretation, and phones can offer navigation guidance, where does the 'tech' stop and start? If one takes a person-centered approach, where the priority is meeting the users' needs, a human sign language translator and an AI translation on PowerPoint or Zoom provide for the same (or a similar) outcome. Similarly, a Guide Dog and a navigation Phone App are not replacements same/ same, but they are in the same space in terms of the use to the individual. Thus, the question of what is tech remains pertinent and very much a ‘grey area’ that is getting greyer. Hence relying on defining by products is problematic.

- **Ubiquitous mainstream tech is AT:** Personal Digital Assistants (PDAs) is the description of all digital products – including mobile phones – in the APL 1 and it already feels quite antiquated now that mobiles are ubiquitous in much of the world – albeit not always in the Global South. The function that was once provided by a Personal Digital Assistant - offered as a targeted support for a person with an impairment - is now possible through a mobile device carried by most adults (access in the case of poor people is drawn out further, here (GSMA, 2019)). When it comes to understanding how AT can be better provided (through market shaping techniques for instance to reduce cost and increase supply), there is a different response from the global community (and Donors especially) on access to mobile phones than other products. In short, while it is less easy to argue that mobile phone provision to an individual is a development investment worth making, conversely mobile phones are perhaps some of the most useful tools to disabled people (ibid.). Mobile phones are just an example of ubiquitous tech which are providing mainstream solutions which can be of huge benefit to disabled people as AT but are not included in the APL and are not considered an AP at present. Tablets are similar. This leads us to conclude that focusing on an APL is problematic. Mainstream - “helpful tech” (field notes, the head of a major tech company) is increasingly assistive.
- ‘**Future tech’ possibilities need anchoring**: Artificial Intelligence, as an example, is starting to provide one of the best hopes for the proliferation of AT assistance, with the new UNESCO centre for AI recently designing a strand of work specifically on AT. These are just two examples of the way that the frontiers of technology are proving vital territory for the broader goal of achieving wellbeing of AT users. Again, this is largely not assumed to be AT, the solutions will not be provided for, in the same way as traditional AT, and the development sits outside of the usual cohort of actors delivering AT/ AP. Thus, the connection to the ‘why’ is becoming even more important to prevent mission drift into cool, expensive, unusual ideas that look good in the lab but do not work in practice. The conclusion: a human frame on AT access is needed.
- **Mainstream tech for information/peer support is increasingly necessary:** WHO have recently launched an initiative called DATA (Digital AT access) (Khasnabis et al., 2020) which recognises the need to support AT users through direct digital information, and to support carers and families though the same, using technology (usually mobile devices). Similar to m-health initiatives (see UCL’s Institute of Digital Health for instance), this work is predicated on years of learning about how to support health outcomes through mobile and text. This is also excluded from the WHO’s APL. In a sense this can be partly understood as digital support in place of AT, or in support for the services that sit around the AP. For instance, a disabled person or relative might be provided information on support or rehabilitation exercises where there is no rehabilitation service. To be clear, it is not suggested this is a desirable outcome, but in cases of critical lack of access to vital AP and the services needed to support them, especially during COVID-19, it has been a reality. The APL does not take account of the role of technology products in service delivery.

Discussion of this brings into question the idea that AT can easily be defined as priority product-plus-service. Are not AT products very different from medicines? The point here is not that the WHO's work on AT is somehow out of date and irrelevant; to the contrary, it has been hugely successful in setting a global agenda for AT access and is already being revisited ahead of the launch of the Global Report in 2022. Rather, the point is that when the definition of AT as a mechanism for delivering assistance starts to proliferate from targeted tech for disabled people to mainstream tech and human support, it becomes more important to identify the principal reasons for the intervention in order to understand the '*why*', to avoid mission drift.

Questions such as '*for whom is this AT an important priority*?', '*how is an intervention valued as a global development issue*?, and '*what is the end game for this work'*? become fundamentally important. Otherwise, decisions about prioritisation can become wracked with perverse incentives. One could argue that distributing mobile phones in a medium income country is an AT intervention equivalent to providing wheelchairs to slum dwellers in Sierra Leone, a clear, common understanding of what success looks like, is vital and missing.

WHO is clear on what its principles are: AT is for the improved wellbeing of persons with functional limitation, under the broad SDG & CRPD commitments the world has made. However, good as it might be in theory, this is not an operational approach that can guide day to day decision making in the modern context. The WHO understands functional limitation in a health related and hence therefore, medically limited way. Many disability rights campaigners take issue with this association to health and functional limitation, precisely because it is not rooted firmly enough in disability human rights – in fact, the WHO approach is not exclusively focused on disabled people, but rather anyone who needs AT (including large groups of older people who would not be defined as disabled people). WHO does not see AT as a disability issue but an issue affecting many disabled and older people.

These themes will be returned to as the evidence is presented in the chapters to follow, about what DJ is, and how it relates to AT. But this summary is presented here in order that the reader might encounter these debates with some of the background which has been discussed among global leaders over the previous four years since the global community and donor attention turned to AT, and ATscale, AT2030 and the Global Report on AT were established (in 2018).

6.7 Discussion: 'AT for what?' A reflection on the framework

Not only does the debate above open up somewhat of a fissure, which we shall observe at all levels of this study, between the AT sector and the Disability Rights movement. It also identifies the avenues for mission creep by those less well versed in the history of the 'why' of AT than the incumbent WHO colleagues in the GATE team[6]. As tech proliferates, and anyway to reach two billion people with AT, new actors are needed in the space and as participants widen the needs to hold a clarity of mission becomes greater. This is vital if we

---

[6] The current leader of WHO GATE has worked on AT for 5 decades working his way up through a small family AT enterprise and then the voluntary sector in regional India to global level where he has been the 'grandfather' of this work for many years, but he is about to retire.

are to avoid those with other agendas simply promoting their own technology or seeking to fund a development project meeting broader political priorities, being able to incrementally disconnect AT from its 'why', or present AT in line with a different 'why'. I suggest that question needs to be answered about a common operational framework, or rather lack thereof.

Returning to the existing literature for a moment, we can see this lack of framing is already resulting in proliferated action on access which could give rise to the potential for perverse incentives/ actions. As the summaries of the Global Summits on AT contributions show (FCDO, 2018), some actors have framed AT programmes under a strong neo-liberal paradigm which opens up to alignment between AT and neo-liberal assumptions about production (USAID, 2014). Others have shaped interventions around the art of the possible. Others in line with their own piorities. Therefore, an understanding of the value of AT to its (potential) users is perhaps a Stage Zero activity, that has not as yet been translated into action.

If, when the definition of AT proliferates, and we can no longer point to specific products or services as 'in' the category we are interested in, it becomes even more important to understand the rationale for intervention, e.g., AT for what? As seen in the London 2012 Disability Inclusion model (Austin et al., 2021a) and the mission-driven approach set out by IIPP for AT (ref) there is a need to set a clear mission against which all can contribute in their own way to drive forward against a mission. However, it is vital that there is clarity of scope, measurable aims, and clear and evaluated objectives (Austin et al., 2021a) for this to be successful. This indicates that the role of ATscale, as the governance function and global partnership on AT, will become critical. Yet to date a global approach that can be operationalised is not yet adopted.

Holding that question in mind, "AT for what?" becomes a pertinent theme of this investigation. A (humble) comparison is drawn here to the seminal lecture 'Equality of What? (Sen, 1998) which set the tone for the debate on what became the Capability Approach to Human Development.

What emerges strongly from the data, is the need to question more closely what we understand by AT, and rather than make a technocratic investigation into functionality, it seems the 'why' of AT, the rationale for its use – what it enables – is the most important aspect. However, in order to decipher this properly for AT, it is necessary to dive more deeply into the results on DJ first.

Given there is no agreed definition of DJ, I attempted a framing of justice around recognition, redistribution, representation and disability relations. This chapter has not been about interrogation of DJ, but rather a notion of underlining the need for such a framework, and a proposition to redesign the notion of what AT is, in order to appropriately assess whether AT is in fact able to contribute to DJ. The next chapter will consider DJ in more detail to begin answering that question.

6.7.1 A new definition of AT?

Following the discussion above, the following themes have emerged which challenge the traditional definition of AT. The study has found that in order to address the issues of poor disabled people perhaps:

- AT could be better rooted into an understanding of the social model of disability and the human capacity to pursue things of value; reflecting the need to centre disabled people as agents of their/our own futures;
- AT should be recognised as a core enabler of collective and creative practices aimed towards justice since for many, participation requires AT;
- AT is more than traditionally understood Priority Assistive Products (for those with a functional impairment). Mainstream digital devices are increasingly enabling access for many people; there is need to engage with future tech like AI as emancipatory; and service provision is being revolutionised through digital manufacture and material science;
- AT is *for something*. AT is the mechanism toward a wider aim.

From this I have developed a new suggestion for a definition of AT (changes to WHO definition shown in bold).

> *"**Assistive Technology (AT)** is an umbrella term covering the devices, systems and services related to the delivery of assistive products **which** maintain or improve an individual's **choice to do the things they value. AT is a strategic prerequisite to pursuit** of human well-being **and collective and creative justice practices**, for those that need it. Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids are all examples of **traditional** assistive products; **and increasingly mobile devices, digital solutions, and mainstream human-computer interaction also function as AT."***

This definition will be explored further in the chapters to come.

6.8 Conclusion

In summary, the evidence presented in this chapter indicates a devastating lack of AT at all levels – local, national and international. Though local need among urban poor disabled people living in mainstream informal settlements is more acute than those organised autonomously, who have good access. The evidence also suggests there is no common global operational framework commonly adopted to frame the definition of AT, and no common measurement framework. Actors are operating according to their own operational/ institutional requirements under the broad principles of the SDG's and CRPD.

AT is most often defined as 'products plus services' (using WHO approach) and the data supports this as the 'settled understanding' of what AT is in lieu of any other. The WHO approach and link to CRPD were recognised by many, although they are not operational models and there was very little evidence of impact at a local level. In reality the definition of AT is proliferating due to pre-existing challenges to the priority list of what assistance is necessary; increasingly, a lack of access to service is leading to more digital material offering peer support and information, ubiquitous mainstream tech (e.g., mobile), and the potential for future tech (e.g., AI) are also contributing. Meanwhile, there is no evidence of a common operational framework through which to understand AT provision.

This is problematic for several reasons of which two are most significant to this study: (i) there are scarce resources to solve for AT access and if they are pulling in opposite directions this reduces their effectiveness and (ii) without a strong connection to the ‘why?’ it is possible to fund and operate programmes which work against that aim. There is a pressing need to understand ‘AT for what?’ in order to guide both AT’s scope (e.g., what counts as AT) and its purpose (what AT interventions enable).

We now turn to look at the DJ in Chapter 6, before returning to the relationship between the two in Chapter 7

Summary of Key findings in this chapter

- A: AT is absent for approximately 15% of people that need it at all levels. This is a proxy estimate and data is poor. Type and quality of AT are extremely limited in SL. (Section 6.1-6.5)
- B: There is strong and developing global commitment to AT access with associated programmes and donor commitments which show some evidence of implementation and a need for local contextualisation. (6.3)
- C: There is a strong and new national commitment to AT access in SL which has not yet had the chance to show implementation. There is a need for engagement with the poorest people and stakeholders. (6.4)
- D: At local settlement level, autonomous, disability-led settlement members had much better access to AT (70%+) than those in ‘mainstream’ settlements (15%) where disability identity was often hidden/ ignored. The variety and quality of AT was also better. (6.5)
- E: AT is most often defined as ‘priority-products-plus-services’ linked to CRPD (using WHO approach) and the data supports the fact that this is the ‘settled understanding’ of AT used globally. (6.1-6.6)
- F: However, in reality the definition of AT is proliferating and so it is more difficult to point to specific products or services as ‘in’ the category we are interested in. (6.6). Therefore, it becomes even more important to understand the rationale for intervention e.g., *AT for what*?
- G: While the WHO approach and link to CRPD were recognised by many, there were no common operational models of (disability) justice, and therefore an understanding of the framework ‘for what’ is needed. (6.7)

7 Disability Justice

7.1 Introduction

We saw in the first empirical chapter that there is a need to understand ‘AT for what?’ in order to guide both, the scope (e.g., what counts as AT) and the purpose (what AT interventions enable). Now, I want to investigate how the ‘for what’ could be better aligned to our understanding of disability justice. While the dynamics of the relationship between AT and DJ are explored in depth in the third empirical chapter, what follows here is a deeper dive into the meaning of DJ in context, offering critical evidence from the data as to the wider claims for disability, and how they are framed.

The first section of this chapter considers the evidence in terms of the understanding of DJ, as in Chapter 6, starting with a recap from the literature review (7.2). The chapter then moves on to present the evidence on the understandings of DJ internationally (7.3), nationally (7.4) and locally (7.5).

The second part of the chapter then summarises what the data reveals in term of the claims making around DJ from the perspective of the urban poor disabled people in the case study themselves. It is organised according to the analytical framework in subsections on representation (7.6), recognition (7.7), redistribution (7.8), and disability relations (7.9). Although the first part of the chapter is organised geographically, this second section takes the knowledge and builds it into the discussion against the framework. The final part (7.10) brings the discussion back to the literature and draws conclusions as to what the study reveals about DJ in this context, and offers enhanced definitions of the DJ ideas presented in the framework. Chapter 8 then considers the dynamics between the two.

7.2 A recap on extant knowledge

As chapters 2 and 3 set out, it is not possible to extrapolate a pre-made notion of DJ to inform policy and practice, in this case of AT, from extant knowledge and literature. In fact, this work is an attempt to add evidence to that pursuit.

It is worth restating that the overarching guide on disability inclusion globally – referred to often in the literature, and the data – is the Convention on the Rights of Persons with Disabilities (CRPD). CRPD exists for the purpose of protecting and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and respect for the dignity of all people who have impairments which interact with barriers in society to hinder their full participation (United Nations, 2006). However, as it has been discussed, this is a broad global convention, and therefore lacks operational clarity, or local recourse to justice. The literature review also set out traditional notions of ‘mainstream’ justice and the fact that these theories do not always take good account of disability. Vice versa, disability inclusion is not always grounded in pro-poor justice approaches either. This is practically noted too. In my day job I often see day-to-day programmes seeking inclusion for disabled people which proffer tools or interventions that actually provide for a reification of the identify aspects of disability, at the expense of a deeper connection to the wider struggles for parity of participation for all humans.

As there is no globally adopted definition of DJ, Fraser’s Parity of Participation (Fraser, 2000), an inclusive justice framework, albeit not disability specific, was married with Sins

Invalid' (Berne et al., 2018) DJ principles in Chapter 3 and adopted as framework for analysis. The data is summarised below to help build out the notion of disability justice as understood in terms of representation, recognition, redistribution, and disability relations. However, this will be looked at to start with in terms of geographical location, and then by the elements of the framework.

7.3 Internationally, what are the dominant understandings of DJ?

Primarily, it is necessary to confirm, without ambiguity, that the only commonality among the responses from the international participants in terms of a disability justice or inclusion framework or approach (and by no means everyone mentioned this) was the CRPD. The following was probably the most emphatic contribution, from a global disability leader:

> *"[Disability justice means]… Inclusion for persons with disabilities. Equal access to all human rights, equality of opportunity. Reasonable accommodation and universal design – all 52 elements of the convention. The north star of the movement is the convention – the north star, and the road map. It's very technical… it's a road map. Not only does it provide for the outcome, but also the steps along the route for the [signatory] State Parties."* (D-08)

Support for the CRPD positively correlated this international expert's position with the views of other leaders, in broad terms, but no one else identified CRPD to be quite such a practical guide as D-08. One leader mentioned the limits of the CRPD, and the calls to enhance it:

> *"I don't think it [the CRPD] is very strong, it doesn't 'declare' much in terms of rights to tech and where it does this involves 'progressive realisation' – as long as a country is on the right road, even if it doesn't expect to get there very soon, its ok. Some have called for a specific 'General Comment' on AT. But there is some resistance to this too. The CRPD is an implement of persuasion."* (D-06)

This relates to the fact that claiming against the CRPD is not much of a reality for many people living in low-income communities, even when the terms of the CRPD have escribed national policy commitments. It is hard to translate the 'rights' of the CRPD into 'realities' for poor disabled people as we can see through the lived experiences presented in these chapters. The comment also reflects a little of what was shown in Chapter 6, about the potential for disconnect between what feels, looks and sounds good internationally and what the experience of that positive approach is for poor disabled people in a low-income country like SL. I take from this that while the CRPD is important, hard won and principally significant, it is neither a guide for day-to-day operations, nor an immediate route to claiming for justice, especially in low income communities. As (Wickenden et al., 2022) found when considering mainstreaming employment and disability – while much literature considers the importance of CRPD, what happens in practice is less well documented.

And to test for terminology, there was often no real distinction made between 'disability justice' and 'disability inclusion' (as one might expect from a group who did not have a common framework for either), though the former was sometimes felt to be stronger and more radical, as one disability sector leader mentioned:

> *"To me when we talk about inclusion and social justice there is little fine difference between these – if you ask me to flag one, social justice – humanity – value: everyone has the same rights and opportunities. Fundamentally. Not medical justice."* (D-10)

However, some of those interviewed did see the value in DJ as a specific term. The following quote exemplifies the argument:

> *"This term (justice) needs to be used more often, as people don't think of the lack of inclusion as an injustice, and when you start looking at it from this perspective, it implies we must do all we can to make sure this inclusion happen - changing the way people think, putting to place policies and legislation so justice can be delivered. A lot of the reason why inclusion is not possible in Africa, is due to policy and law. [We need] … to evoke and demand inclusion as a right. So it has to be demanded, not just requested."* (D-2)

Above, an 'expectation of exclusion' is revealed, similarly to as was noted in section 2.2.7., as a form of internalised stigma. Here this is articulated alongside the reflection that inclusion must be demanded. Whilst D-02 clearly acknowledges this, the initial half of the quote explains the deep work that is needed to overcome this type of stigma, since many disabled people will lack this framing and instead are living with the expectation of exclusion. The difference between inclusion and justice is clearly articulated when considering it in terms of the work of Sins Invalid (Berne et al., 2018). This DJ approach reflects well what some of data showed (although no clear articulation was made explicitly). The notion of claims-making as a radical, community led inclusive citizenship practice (Kabeer, 2005), along the lines of Holston and Appadurai's deep democracy from below (Holston and Appadurai, 1998) seems to fit better with the data than inclusion. Rather than an approach to inclusion which simply seeks to include disabled people on the same (bad) terms as other poor people, this reflects the debate I elaborate on more in chapters 3 and 9 about what type of disability inclusive justice would support the claims making of this group of poor disabled people. Would it be the disability equivalent of feminism for the 99% (Arruzza et al., 2019) or 'lean in' (Sandberg, 2015) style corporate equality (Fraser, 2021b)?

I adopted justice as the core aim of this study, building out from these ideas of radical and active practices – claimed and owned by the communities themselves, because it seemed to better fit the data and the lived experiences I observed, and sought to address its definition through this work. However, it must be said that often the participants referred to inclusion more broadly for more clarity of mission, as we shall see.

No definition of justice found common parlance directly in the data, though it is clear the principles were seen as important. There was one international expert who proved the rule by exception by directly referencing Fraser:

> *"On Disability Justice we are building from the knowledge of Gender Justice, and building from Nancy Fraser's concepts – and although it is theoretical, so many movements have used it to claim rights; Redistribution – of resources they need e.g. AT; Recognition - of they need a space where this can be claimed; Participation - more opportunities for decision making."* (D-05)

So, while no common understanding of DJ was found, nor any model of disability inclusion had been commonly adopted below the broad commitments in the CRPD, the idea of DJ, understood as more disability inclusive action, was supported by all, and by some very explicitly as has been shown.

When asked about how this thinking on disability informed work on AT, no one had an institutional definition to offer which guided their day-to-day work. Additionally, the most oft-given response from the international AT experts interviewed was that they did not have a definition to work from or in fact another team led on this aspect of work (often a disability lead, where they existed), for example:

> *"I don't know, ask [REDACTED – the Disability Inclusion team], it would align with the CRPD, [REDACTED – our organisation] doesn't have its own definition."* (D-03)

This result is, in part, a product of having interviewed a sub-set of AT experts, rather than disability leads. Yet, these people are in fact *the* central figures delivering AT programmes globally, not the disability leads. Thus, it is significant that there was a consistent lack of connection to a broader clarity on definitions and approach for disability inclusion or DJ. This is a fundamental finding of the study.

That is not to say there was a lack of knowledge about the topic in all cases, and some individuals made gallant and very comprehensive efforts, when asked directly, to define DJ themselves:

> *"What I think of it [disability justice] is as Human Rights for persons with disabilities. I see it as equal access to education, health, jobs, community… but it is not just about access, it's about everything…. Its about stigma and discriminating perceptions too… so for me, its about looking at everyone fairly….we should be giving everyone the same opportunities. As far as is possible."* (D-07)

Some participants put this lack of an operational framework on DJ or disability inclusion down to a lack of data to inform an agreed approach:

> *"I think we're not there yet, we're not where we need to be. We [Organisation - REDACTED} have a broad policy on non-discrimination, but in my opinion we need more…we lack a framework on disability. But we don't have enough data."* (D-01)

From my own research notes (2019-22), I can conclude this relates to the newness of AT as a global agenda and also to the new actors who have come into the AT space from other areas of work, including NGOs moving from mainstream delivery, donors addressing AT for the first time, and global health agencies moving toward activity on AT. It was an explicit aim in the setting up of ATscale and the AT2 030 programme to crowd-in new actors to the space. However, this also suggests perhaps an even stronger reason to connect to the 'why' of AT in terms of its role in a wider struggle for justice. New entrants to the sector may be naturally differently motivated, and therefore this highlights the importance of a common notion of what good is, being missing.

If we consider the findings of the framework on London 2012 disability inclusion model presented in Chapter 2, a 'common mission and understanding of the scope and objectives' is core and key to success (Austin et al., 2021b). Thus, this lack of such, is significant to underline and will be explored further in the next chapter. It is a reflection too, that this is potentially a failing of GDI Hub, or rather that we could have taken a stronger role in ensuring that new actors had a strong disability framework within which to operate – in part a motivation for this work!

Another key factor mentioned by international actors was the consideration of how AT intentions are operationalised from international to local and national level. As one international expert mentioned:

> *"Our organisation does not use an 'end goal' for our work on disability. We talk about disability inclusion, and we expect to see organisations of persons with disabilities participating on an equal level with others in all spheres of life…local people are much closer to the realities."* (D-10)

This lack of measurement of outcomes is perhaps unsurprising given the lack of a DJ framework overall. Further, the transferability of global approaches to local context was a theme raised by the participants:

> *"A global framework can be helpful, but once the government have a route to see the solution… they desire to have quick results and the need to go systematically. There is often a high degree of political uncertainty and a changing context….we need to take that global level framework and make it contextually relevant…as much as people have an understanding of need there are tough decision to take [nationally] based on limited budgets."* (D-01)

The vital reality of national implementation was raised again and again as important in the process, with an implicit assumption that there is a fully functioning global framework to transmute locally; there was no evidence to suggest this was the case in this study. Thus, any global framework would need to be operational, and nationally and locally responsive.

In short then, the global evidence reveals that DJ was broadly supported but only contextualised under the CRPD, that common definition of DJ or any common operational framework used to guide AT work under disability inclusion or justice ideas did not exist, and the term justice is related more strongly for international participants. Thus next the national level evidence is considered.

7.4 Nationally, what are the dominant understandings of DJ?

The 1991 constitution of SL makes provision for promoting and safeguarding the welfare of disabled people, and as outlined in Chapter 2, SL signed the CRPD in 2008 and put into law its Disability Act in 2011. The Disability Act (C-DAct) did not provide a specific definition of DJ or disability inclusion, but it offers a definition of discrimination which is outlawed.

Discrimination is:

> *"treatment of a person with a disability less favourably solely or mainly on the ground of that person's disability and includes using words, gestures or caricatures that demean, scandalize or embarrass a person with disability" (C-DAct)*

The Act also does makes provision for the following (all language is used as in the Act):

- A **National Commission for Disability** with an elected chairman the object for which is 'to ensure the wellbeing of persons with disability';
- The **right to free education** 'for every person with disability… in tertiary institutions and protection from discrimination in education';
- Provision of **free medical services** in public health institutions (but this provision includes the right of a medical practitioner who 'detects a disability' during a medical examination to submit to the medical board a preliminary certificate showing the kind of disability or potential disability a person is 'afflicted with';
- Compulsory health screening for disability detection for children;

- **Prohibition of denial of employment** on the grounds of disability, tax incentives and contractual compliance;
- The right to a **barrier free environment** (inclusive design of building and public spaces) with the potential to give adjustment orders where this doesn't happen;
- **Access** to public transport, sports and recreation facilities;
- Voting access ensured by the National Electoral Commission;
- A **fund** to support persons with disabilities, managed by trustees;
- **Ad hoc additional facilities** (sign language on TV is mentioned specifically);
- Government **Disability Units** in each Department;
- **Significant fines for carers who conceal** and don't register persons with disabilities;
- The power of the Commission to take legal action and raise Statutory Instruments.

(C-DAct, 2011)

This is a considerable piece of legislation with some important provisions that help to understand what type of DJ the National Government believes in. This would be an 'equality in law' justice, but with a paternalistic flavour of the medical model of disability as evidenced by the notions of medical professional assessing and labelling disabled people and the requitement to 'register them'. The value of participation is recognised in the voting aspect, and that ties with the data we have from slum dwellers who did vote – but for ordinary Sierra Leoneans no other aspect is considered, for instance, support for ordinary disabled people to stand for election is not mentioned.

This type of disability inclusion does not seek to redress strategic participation directly, though employment discrimination is outlawed and there is technically free access to health and education in law. It also does not seek to align disability justice with other struggles – for instance it does not recognise intersectional experiences of disabled women. Nonetheless, the reference to non-discrimination and particularly to the theoretically free service access (education and health) was welcomed and much needed by participants in this study. However, the evidence suggests, there is considerable concern over implementation, and these provisions were not available in practice:

> *"It is disturbing to me, myself, that the Disability Act was in 2011, and by law after 5 years the policy in the act should be done … but it's not happening. I am pleading to govt to implement the Act: to provide opportunities of persons with disability; the right to get employment; the right for each ministry and Government office to … the things in there are very nice, but if I have anything to say to them its that: 'lets do something'!* (E-01)

The establishment of the Commission was also considered a positive move by some participants. But the Commissioner (in the 2018 meeting which I attended) was a semi-famous radio DJ who was politically appointed. Thus, while the Government was supported for having established a National Disability Commission, there was some concern that this body functions at the behest of the Government that funds it. One of the participants interviewed in 2021, mentioned this:

> *"The Commission is existing, but the Commission cannot bite the finger that feeds it, so even in terms of advocacy, they won't - because they see it as criticising the Government. For me, I was thinking that the Commission should be independent".*

> (E-2)

No other direct reference to DJ was found at a national level. It is helpful then, to now consider what DJ means in practice to participants.

7.5 Locally, what are the dominant understandings of DJ?

Locally, the most commonly discussed notions of DJ among disabled people in the mainstream settlement communities related to the terms set out by the provision of the Disability Act. Most, but not all, disabled slum dwellers knew about the 2011 Act. This was most often expressed through some form of dissatisfaction, ranging from irritation to despair, that it has not been implemented in practice, as set out above, and below, where claims for justice were clearly made.

> *" . . . The government should provide for our necessities because we are citizens of Sierra Leone."* (A-TB-07)

The following quote summarises what slum dwellers in the mainstream settlement expected.

> *"…we are expecting good schools, good toilets, good bridges, and a good road for the community benefit . . ."* (A-TB—03)

These were not disability but mainstream concerns. The participants' version of justice was to be able to have the necessary things for the community and be able to share them. As the mainstream disabled slum dwellers lived in precarious conditions, where water, shelter, infrastructure, education, and health services were lacking, it was the case that disability-specific concerns were often raised second, behind the common concerns of the community.

The disabled slum dwellers in HEPPO, the autonomously organised settlement, were also concerned about the day-to-day claims for a basic standard of living:

> *"Our major problem is the shelter for the community. We have children, but the place where we live is not ours and we have been here 4 decades, but we cannot be here living here for long time. In 2018-19 – 2020 we lost 5 of our disabled colleagues because you did not have the proper shelter as a result of chronical malaria."* (E-01)

However, they were more adept at advocating for their own needs as disabled people, using local and national Human Rights legislation in their favour, and had relied on these provisions to avoid eviction in the past:

> *"We have been issued an eviction in 2019, but we went through a lot of challenges, I had to call the human rights commission of SL – I wrote to them and explained about our condition and concern for our CS [Civil Society] organisation. I asked the chairman to complain to the HR commission."* (E-01)

HEPPO is registered as a CS organisation and its leaders believed this was because they were collectively organised advocating for themselves:

> *"We always say 'nothing about us without us' so we have to be on the front line … the more we speak for ourselves the greater the attention. The more others speak on our behalf the more we are at the back."* (E-01)

This is starting to touch on the representation and recognition aspects of justice, so it is now helpful to look at the participants' specific claims about DJ, and which I now consider in relation to the elements of the analytical framework.

7.6 Representation claims for disability justice

This following sub-section will present evidence for that first element of the analytical framework representation. In Chapter 3 I set out the potential hypothesis of this element of DJ as follows:

> *"Representation:* ***…disabled people participate and lead****.*
>
> *(Chapter 3)*

The data revealed that representation was valued, with some slum dwellers keen to take a role in representing themselves and making policy-makers aware of their situations and needs. These tended to be the disabled slum-dwellers in the mainstream settlements who were more engaged outside of the settlements, e.g., in education or employment, or those from the disability led settlement. Monica, the finalist of Housemate Salone (equivalent of Big Brother) was pointed to as an example:

> *"We need to advocate for our rights so we can do more. We are leaders too because so many people think that disability people cannot do that, but Monica, she is blind, but she was advocating at SLBC radio station."* (E-03)

There was a strong sense in HEPPO that poor disabled people must be the leaders of their own struggles:

> *"Who feels it knows it. Disabled people understand how to fix the problem because they are the ones going through the middle part of the problem. That's why it's important for disabled people to be leaders.".* (E-02)

Participation in political processes was valued and important too. It was the primary demand of the SL Persons with Disabilities Manifesto in 2018 produced by SLUDI;

> *"We, the disability community of SL, call on political parties to invest in . . . the inclusion and participation of PWDs in the political process."* (SLUDI, 2018);

and it was mentioned by many of the disabled slum dwellers in the interviews, as a fundamental right to be able to participate in the political process:

> *"I vote every election, I have to exercise my right to vote because it is my right."*
>
> (A-D-3)

Almost every disabled slum dweller in Dworzark and Thompson Bay indicated that they voted at election time, but they were provided with assistance by political parties to do so, often being supported to get to ballot boxes, in lieu of AT, with special lines for those that could not stand in the long queues. Some of the participants felt this was partisan and somewhat cynical:

> *" . . . at the end of the day the election comes and they promise and then nothing is done. During the election they drive me and then I never see them again."* (A-D-04)

However, this experience of being supported to vote in lieu of AT was not unique and international experts recognised this unfortunate situation:

> *"It is always distressing to hear this and I'm also very concerned that disabled people are 'wheeled out' or 'carried out' to vote, because it focuses on the frequency of participation in voting rather than meaningful participation in democracy."* (D-06)

As we saw above in the national legislation, the limit to what was acceptable participation by disabled people in the study in Freetown, was clearly set (by others) at casting the vote, as one disabled woman commented:

> *"Disabled people are not allowed to do things, I was told I wasn't allowed to staff a ballot box . . . and I was not too ok with that, because I wanted to do it."* (A-TB-01)

Only a couple of participants mentioned taking part in campaigns or any other informal or formal political activity, most felt excluded from meetings of both types, however important:

> *"It is not the same [for persons with disabilities], because like, for instance, I am having difficulty to walk, so if they call for any meeting that has to do with development, I cannot be able to attend or participate so those that are the non-disabled are the ones that can be involved in the process."* (A-TB-06)

The consequences of a lack of representation were evidenced in Dworzark and Thompson Bay. Slum dwellers had been represented by non-disabled slum dwellers at FEDURP community meetings for some time. The intention of FEDURP, as mentioned, a voluntary organisation run by and for urban poor people, is to do more collectively than what individuals can do alone, promoting their values of speaking for themselves, using information as power, and saving toward the things they need in the community. While FEDURP members do fantastic work, until 2019 their leader shared that they had not considered issues of disability.

Once FEDURP started working with disabled people, they quickly realised the need for representation and made open and public statements to the effect, at a public meeting when International Day of Disabled People was celebrated for the first time in the settlements. In Thompson Bay, the Chair of FEDURP made an impassioned speech, a long and powerful contribution made and recorded in Krio. A translation is as follows:

> *"I'm sorry. In the past FEDURP has worked to build community facilities like toilets without consulting you, and we will never do that again."* (Disability Celebration Day, Notes, Thompson Bay, 2019)

FEDURP recognised the need for representation because they already valued representation of slum dwellers as a means of justice themselves. They had built very low resource toilet facilities as a community, but it was not accessible to the disabled people; once disabled people started participating and explained this, the leadership of FEDURP instinctively understood why representation was important to avoid such errors in the future.

Further, disabled people in the communities responded positively to the desire to participate more, when interviewed were clear about wanting to participate more in FEDURP, even setting out their own Savings Group in Dworzark during the time of the research. However, the need for AT, both to facilitate representation, and as a goal of that collective activity, remained core:

> *"I think that we should come together to sensitize ourselves on what we should know as disableds [sic] having one common goal. Our expectations should not be always high, but rather to advocate for support . . . with some AT like, wheelchair, crutches and other supporting equipment as disables, and to see how we can better our lives with this assistance."* (A- TB-O6)

In the HEPPO community the issues were very different because AT was available, and because the community was led by disabled people. Thus, there was representation guaranteed in the informal structures and that was facilitated by AT access. Yet beyond the settlement many issues were the same regarding access to services, jobs, and stigma. This emergence of the general struggles of the urban poor versus the struggles specific to disability was a strong theme in the data. I want to look at it more below.

7.6.1 Representation claims - the divergence of struggles for inclusion or mainstream versus specific representation

Many of the mainstream NGOs and Community Based Organisations in SL were not well versed in disability issues, and though they were making claims with, and on behalf of, communities that disabled people were a part of - claims that disabled people did prioritise - they did not always take good account of disability. One local stakeholder commented on this:

> *"Awareness of disability is developing [among mainstream community organisations in SL] … before now [REDACTED – our organisation] found out that we can partner with SLUDI to develop programmes. The [REDACTED - international network] arrangement with the aspect of disability has not been too clear…its been down to local teams to figure it out for themselves…[but] now if you include disability issues in the country programme its ok with them. In terms of advocacy we remind [REDACTED - organisations working on urban poverty in SL] that as well as issues of poverty and accesss to services, how can we have a component about disability…that speaks to disability issues?"* (A-S-01)

This quote demonstrates some of the key thinking on representation that was starting to take place among mainstream organisations in SL at the time of this study; there was a stirring of ideas about disability, but not yet disabled people participating, on the whole.

The consequences of the lack of participation appeared greater for disabled people living in mainstream settlements, in conditions of precarity, who face a natural compulsion to claim for their basic needs first, before articulating their claims for rights as disabled people. This had two impacts. Firstly, disabled people's voices were usually unheard within the group of poor people claiming for their basic needs. Secondly, their subsequent claims for disability rights often went unspoken, or were deprioritised among the considerable and pressing issues of the urban poor.

This is perhaps to be expected. The representation of poor and African disabled voices is well documented by Ned (Ned et al., 2022) and others. For group of people who already find participation a struggle due to physical barriers, the notion of leading did often seem very unusual. This was the case for both, the disabled slum dwellers in the mainstream settlements, and the leaders of organisations of the urban poor. However, this changed throughout the research as participation led to better outcomes (for instance the disabled slum dwellers setting up their own savings group in Dworzark).

Taking this evidence together, I want to now start to elaborate on how this element of the DJ framework might be characterised.

7.6.2 Adding more to the definition of representation disability justice

Reflecting the whole evidence, I have collected, I would like to suggest that for poor disabled people representation could be indicated as follows:

Disability Justice: Representation - disabled people participate and lead

Disabled People and able to identify, speak about, collectivise around, influence, lead and nominate other to lead, policy and practice on issues which are valued; at each constituent level (local, national, international); both formally and informally. The voices of disabled people from all backgrounds are understood and valued - alongside others - and leaders who are (poor) disabled people themselves are seen and heard as commonplace. Political processes are democratic inclusive, accessible, and pluralistic

These words are not intended to be perfect. They are, rather, a starting point for discussion. They provide the basis for further investigation, ideally by poor disabled people themselves (as goes for all of the ideas in this thesis). I have chosen them based not just on what has been witnessed through the study, but also what has been missing. They reflect the spaces where participation could and should be, based on the evidence I found at every level. This will be brought together with the other elements of the framework (tested in the other empirical chapters) and discussed further in Chapter 9.

We now move on to look in more detail at the DJ claims of urban poor disabled people as they relate to recognition.

7.7 Recognition Claims for Disability Justice

As Chapter 2 set out, Fraser (2005, 2007) used recognition as shorthand for what she called the cultural elements of her theory of Parity Participation. It is precisely the balance between the struggle for recognition of identity, and the context of connection to the broader struggles for redistribution, that motivated her addition of this factor. A short description was developed and set out in Chapter 3 for this study, as follows:

…***disability identity is recognised positively***

(Chapter 3)

This section will now consider how the evidence relates to this idea.

One of the main claims of disabled slum dwellers was for recognition. This is summarised in the following quote:

> *"I say give us the chance to be part of you, and for our voices to be heard."* (A-TB-07)

A couple of participants believed that if disabled people could be recognised as leading the charge for the claims on behalf of the whole community, they would earn respect:

> *"Well if we come together ... the first thing we ... need is water ... so if we come together as one, we work with the stakeholder in the community, we bring to other people, we bring everything together and move for water, pipes and material to come here... and make the point. As soon as water is available in the community that is the number one way [to gain respect] because the number one thing that the community does want is done by the disabled (sic)."* (A-TB-08)

This speaks to lack of recognition and its importance to the participants in the study.

7.7.1 Invisibility for disabled people in the mainstream settlements

In 2019 disabled people were 'invisible' in the mainstream settlements with no instances of them meeting together or discussing disability at all, or participating in the settlement leadership. The experience of many disabled people was of exclusion, the following quote was typical:

> *"In this community, the non-disabled are many and the disabled we are few and they are not seeing us as useful people. We are considered 'less' in this community."*
>
> (A-TB-06)

This was often made more significant because of the stigma and shame associated with having a disability identity:

> *"I think that the reason we are not meeting together is so as not to show ourselves to the community...most of these people believe that disabled people always cause trouble...that is their knowledge."* (A-TB-08)

There were many contributions which were indicative of a wish to 'be seen':

> *"I can tell the people with no disability that they should be listening to us disabled [people], because as humans we know the starting of our lives, but we don't know our end, there is a possibility that one day the able might also become disabled."*
>
> (A- TB-07)

This was further evidenced during a side project, which provided rice to slum dwellers (with a focus on disabled people) during the worst of the COVID-19 pandemic. In his final interview for this research the community leader who led this, revealed what they had found:

> *"There were a lot of issues inside the homes which we hadn't anticipated [after working on disability for 2 years]. What we saw is more disabled people inside the homes – including women and children - just not coming out of the home at all as the family think this is the devil and 'witch things' so they don't allow that person to be seen by the community. In this tradition you keep this person in the house so people don't see him."* (E-04)

In common with all of the mainstream settlements visited, the homes in question were perhaps a meter or two square, made of foraged, corrugated iron or tin walls and roof, without bathrooms, wash facilities or water. What shows real progress on disability rights in the community, and is a huge credit to the community organisations working there, is the fact that he then continued:

> *"…because we had done the training, and done the RATA [survey], we used the [WHO AT] picture charts to visit the families and show them what we have learned…. that this is just traditional beliefs…Sometimes they are now going out. There is less stigma because we are seeing the role of participation, no matter what the condition. We are still having calls "someone has told me XXXX can help with what has happened to my child."* (E-04)

There is a strong evidence that community organisations are beginning to recognise disability as a significant issue, yet that support is being provided by the community organisations, not the state sector. What is being drawn out for the purposes of this chapter is the specific invisibility of disabled people in these communities of urban poor people. One stakeholder summarised this well:

> *"I think the challenge is that Disabled People are in slums but it's difficult to identify them. That's why we are very much pleased with the AT project. This has been the first time we have been able to work with disabled people in a community. It has been very more difficult for us in our mobilisations to have more disabled people coming out of that."* (A-S-01)

Many disabled slum dwellers in the mainstream settlements were used to being excluded, and hence commonly did not advocate for their own needs, as is well explained below:

> *"Many disabled people are in the habit of exclusion - when you have been excluded for a long time, your habits change a lot – the limits that have been presented for you, they are attitudinal, or to do with lack of information or misinformation and that contributes to the lack of empowerment. The excluded have been convinced that there is nothing that can be done to get out of this and they have believed that to be true."* (D-02)

What this expert calls 'a habit of exclusion', is what perhaps Sen would call this 'Adaptive Preferences' (Sen, 1999), and what Bruckner (2009) defined succinctly as a preference that is mediated based on the likely options available. Nussbaum (2001) considered the adaption of preferences in relation to gender, which may offer the guidelines for an interesting analysis of disability. While this is outside the scope of this study, certainly the data showed up this ‘*expectation of exclusion’* in many areas. The shame associated with a pejorative identity combined with barriers to participation appeared significant.

Stigma in the context of urban informality has been recently discussed by Baumann and Yacobi (2022) who highlighted the need to join up the debates on infrastructural exclusion and stigma and suggested that stigma is no merely a symbolic forge but has considerable material affects, including the impact on physical health. They further argued that stigma connected to spaces lacking basic services, in this case residential informality, can be used to further legitimise and reproduce ‘otherness’ and ideas of lack of deserving among populations (ibid., p.476). Lemanski (2022) highlighted the need to cross disciplinary silos on stigma. Many academics and practitioners have considered disability and stigma in great detail, and it could be a thesis in itself to do so. But in lieu of the luxury of that scope and scale, I would like to draw out the fundamental ideas that synthesise the findings here. These include the idea that (i) stigma operates against those with pejorative identities (like disability) and those experiencing urban informality or infrastructure exclusion as we have just seen; (ii) stigma can result in adaptive preferences or an ‘expectation of exclusion’; (iii) disability and stigma in the Global South are well documented phenomena. Rohwerder (2018) suggested these are driven by a lack of understanding of impairments and their causes, misconceptions relating to cultural or religious beliefs, shaming, misunderstanding relating to the ability to contribute financially and otherwise of disabled people, and discriminatory legislation and practice along with negative stereotypes.

These ideas also connect to the work of Brown (2006) who has published widely in the popular press around shame highlighting that the opposite of shame is not pride but belonging. Brown suggested shame can be understood as the fear of disconnection or being unworthy of connection which we all have, and that what separates those who experience belonging from those who feel shameful is a belief of worthiness. This comes through courage, compassion, connection and being able to be vulnerable, to be who one truly is (Brown, 2013). Clearly many of these themes resonate with the rationale and reality of exclusion for disabled slum dwellers, especially in the mainstream settlements, who find themselves experiencing stigma, shame and a lack of belonging. I now take this evidence back to the characterisation of recognition.

7.7.2 Returning to the definition of recognition disability justice

As before, I now add to the definition of DJ recognition, which I set out in the initial framework in Chapter 3. This characterisation takes account of the evidence presented above, and in particular it draws out the issues of misrecognition and stigma that were experienced. It also seeks to connect the idea of disability struggles as seen and heard as part of the wider struggles for justice that were identified.

Disability identity is recognised positively

… in all of its diversity; avoiding misrecognition due to the stigmatisation of disability identity, invisibility and reification of disability identity detached from other concerns about justice, in society.

Chapter 9 will discuss this further, and Chapter 8 will discuss what AT did to enable this recognition and the relationship to stigma which was a surprising outcome. For now, I turn to redistribution, the third aspect of the framework.

7.8 Redistribution claims for disability justice

A hypothesis was developed and set out in Chapter 3 for this study, relating to redistribution and DJ. It is repeated here, as follows:

> …***disability poverty is tackled***
>
> *(Chapter 3)*

Here I am using the term 'poverty' very broadly, to talk of more than simple access to financial resources, but rather the elements of access to resources that support human wellbeing, as (Sen, 1999) described, and as set out in Chapter 2. I will now consider the evidence around redistribution.

7.8.1 The overarching claims of communities for redistribution

As part of the DPU SP9 of AT2030, participatory research was conducted with disabled and non-disabled participants to set two overarching 'aspirations', using a Capability Approach framework (Sen, 1999). This identified priorities in the communities through participatory work. Affordable housing (Dworzark) and healthy living conditions (Thompson Bay) were the collective community aspirations prioritised, with the 'most transformational' aspirations identified as affordable and accessible healthcare (Dowrzark) and inclusive mobility (Thompson Bay). The participants made a textile banner to hang for the International Disability Day Celebrations, shown in Figure 20.

Figure 21 Slum Dwellers in Thompson Bay with their chosen aspiration: Inclusive Mobility. Photo by Angus Stewart.

Disabled people in the communities were half of the group and were active participants in arriving at these aspirations, which represented a consensus position. The HEPPO settlement did not do this work, so a direct comparison cannot be made, however, HEPPO members also talked about the basic needs of life as the priority for claims making:

> *"The priority of the people remains the same; water, housing, health, education. It's just that the financial aspects are seriously impacting the people."* (E-02)

Thus, we can conclude that redistribution of resources towards meeting basic needs of those living in precarious conditions, was a priority in both 'mainstream' settlements and in HEPPO. The commonality of justice claims among disabled and non-disabled people living in urban poverty does infer that conditions of precarity were of paramount importance for both of these groups.

Given that the disabled people in the mainstream settlements had never articulated their needs as disabled people collectively or individually in community meetings, it suggests that articulating their claims as disabled people, came secondary to articulating the claims of the whole community. Potentially because of this 'expectation of exclusion' identified earlier. Nonetheless, redistribution was needed and highly valued. Especially in increasingly difficult economic conditions.

7.8.2 Inflation and access to income

Since the pandemic, massive price inflation has been seen in the Freetown hugely impacting the poorest people. As one participant noted in one of the last interviews:

> *"600,000 Le (minimum wage) can only buy a bag of rice now (520,000 Le) with no money for food, school, sauce, salt. All around the community people are grumpy because they are hungry and things have become too expensive. Only 20% are working, most are unemployed. Rent and landlords are charging a huge amount for the housing. They are charging in US dollars."* (E-02)

In October 2021, the World Bank reported this trend too, though at a lower level than anecdotally reported by community members, potentially reflecting the fact that the poorest experience the harshest realities. World Bank stated:

> *"Headline inflation [rose] sharply to 10.2%, reflecting an increase in food and fuel prices. Food inflation reached 17.1% by end June [2021]…Problems of poor infrastructure and widespread rural and urban impoverishment persist despite remarkable strides and reforms." (World Bank, 2021)*

Everyone in SL, spoken to in 2021, raised the issue of rising prices and fewer jobs available, thus making access to income and redistribution of it towards the poorest a core issue for slum dwellers and stakeholders. From this I conclude that access to both income and other resources are a core requirement of justice for poor disabled people. However, I want to be very careful to avoid valorisation of access to labour markets which seek to reinforce injustice.

7.8.3 Assumptions about productivism

As referred to in the literature review, productivism (Mladenov, 2017a) has been used in terms of disability to refer to the notion of value being proffered based on productive output aligned to markets. Further, “productivism is conceptualized as a mechanism that generates cultural and material invalidation of those considered to be unable to work” (ibid., p.1109). Though his work focused on the transition from state socialism to neo-liberalism in post socialist Central and Eastern Europe, I believe Mladenov’s approach is useful in thinking about the context of disability and justice in SL. This is because the two conditions, which use the reification of wage labour as a means to substantiating results, are both relevant to the study; firstly, the cultural stigmatisation of those (disabled people) who are unable to work, and secondly the material marginalisation of those who are unable to work (ibid.). To take the first issue first, we have discussed stigmatisation and misrecognition above, but the 3% employment rate for disabled people in SL, and the need to rely on means such as begging, reinforce the stigma and perceptions about disability and charity – the need to be helped. I discuss this more in Chapter 8. The second issue relates to the simple fact that disabled people are poorer because they are not able to engage in livelihood activities. AT both enables this access as we shall see in Chapter 8.

However, when recognising redistribution of wealth and assets, this is not simply a case of suggesting justice will be well served if poor disabled people are able to access short term low paid jobs on the same bad terms as others, but rather, as Fraser argued (ref), [OLD IS DYING]it is a part of a broader struggle to remodel the whole economic and political system. Participation in this struggle for many disabled people will require access to AT, as we will come to discuss. I return then to a more coloured characterisation now, below.

7.8.4 Returning to the definition of disability justice redistribution

It is shown above that access to financial resources is a core concern for disabled people, and all people in Freetown’s settlements, but it is also the case that the community also needed access to resources beyond money. They also wanted to prioritise inclusive health care and transport, albeit often to enable access to livelihoods. Therefore, I have developed a further characterisation of what is meant by DJ in redistribution terms below. This draws out the explicit issues highlighted in chapters 2 and 3 about the issues associated with neoliberalism and the assumption that productivity is a prerequisite for ‘deserving’ access to goods or service, support or income. It also seeks to avoid the reification of disability identity within the wider struggle.

Disability poverty is tackled

…within an overarching strategy for redistribution of wealth and wellbeing (from the few to the many). Overturning maldistribution is not hindered by implicit or explicit normative framing around productivsim, or displaced by identity politics.

Again, this characterisation is offered to give meaning to the definition, and for sure requires further testing. I return to this in the discussion in Chapter 9. I now move on to look at the fourth element of the framework, disability relations.

7.9 Disability relations claims for justice

I now look at the fourth element, under the following definition, which was intended to capture the themes of radical accessibility, recognising intersectionality and building solidarity:

No body/mind is left behind in a broad-based movement for justice
(Chapter 3)

I now look at the evidence. SL has a number of active disabled people's organisations. The overarching body is SLUDI. SLUDI has a strong voice at a national level, but the evidence suggests that DPOs and Organisations of the Urban Poor are not well connected to each other. One slum dweller commented:

> *"Their (SLUDI) offices are very far away . . . the last meeting I went to [in 2014] I told them that I wanted to be part of their organisations. They took my name, but they never called me... They never came here but if they did, they could sensitize the community and explain the usefulness of disabled people. So, I'm sure that if SLUDI start coming here and do some sensitization, the community will see that all the people that are part of SLUDI are (useful) disabled people."* (A-TB-08)

This quote recognises two important things. Firstly, that the DPO response to reaching into the poorest communities is not successful, and secondly, that the CBOs working on poverty require, in the words of the participants, sensitisation to the disability issue. This is a pattern repeated in the data. This is also noted at international level where DPOs are not central to the global push on AT access, and the global work on AT is not tied to an explicit framework for justice.

The data suggests strongly that the reality for disabled people in SL is that disability identity is not respected, and is often hidden completely, so there is a fissure between the actions of disability organisations and the actions of urban poor advocates which can leave poor disabled people lost between the two. This affected the ability to build solidarity and certainly affected accessibility of claims making. Bodies and minds were also left behind by the lack of access and inclusion.

The second point is around intersectionality. There was a disparity in the RATA data about access to AT in the mainstream settlements (as set out in Chapter 6), in which disabled women had less access. Similarly, though I did not measure impairments clinically, it was the case that some bodies/ minds were not able to participate in the community at all. Those with more stigmatised impairments, such as learning difficulties or mental health conditions, were not evident or present, though were later identified by E3. The lack of interpreters meant that a deaf participant could not take part too.

Thus, in terms of disability relations, the evidence suggests that poor disabled people in the mainstream value collective action, both within and autonomously from other social movements of the urban poor. However, this is not currently taking place.

7.9.1 Returning to the definition of disability relations

The words I have added below seek to address this vital and pressing need to offer what Pineda (2015) called radical inclusion (*Dr. Víctor Pineda*, 2015)*,* in the struggle for justice.

No body/mind is left behind in a broad-based movement for justice*;*

both the intersectionality between disabled people and the relations between disabled people and wider social movements are recognised and supported. Disabling relations are overcome. Disability justice is a core part of a broader economic and social justice movement.

Again, these are not perfect words, but rather a characterisation of the types of issues that are arising from the data in the struggle for justice for this group.

7.10 Discussion: what is DJ?

In general, to get to any mission or goal, be it disability inclusion, ‘a man (sic) on the moon’, or vaccine equity, we start by setting a common global mission, rely on proxy indicators, and plot first steps. Mazzucuto called this mission-setting (Mazzucato, 2015). When considering how mission setting supports global programmes and initiatives, the UCL Institute of Innovation and Public Purpose (IIPP) needs to be mentioned given their fundamental work in setting a missions agenda which encompasses missions as wide as climate change and health care, as well as how topics such as AT fit within these (Albala et al., 2021). This idea of a central mission through which to drive disability inclusion is also what we found necessary when we studied what model has been used to deliver disability inclusion around the London 2012 Paralympics Games (Austin et al., 2021b). Yet the mission seems to be missing here. What the evidence shows, is a broad intention that DJ is a good and positive thing, but it lacks clarity on what it means in practice operationally, by those driving for change, and lacks involvement of the people who matter most.

The issue here is that without a common understanding of what is aimed for, any mission can result in a divergence actions unless actors are incentivised to drive for a common objective within a common normative framework. In my experience working in global health programmes for ten years, the first steps in any initiative or intervention are usually set according to defined normative goals and framework and go on to set the tone for others (when it is done well!). In the case of London 2012 these were ‘the most accessible games ever’ (ibid.). Actions are then prioritised and can be either targeted (in the case of disability inclusion, naturally for disabled people) or broad (focused on catching all people in poverty) if addressing economic exclusion. These first steps will often be either deep (reaching the most excluded first) or wide (reaching the widest group first). Thus, it is only when these interventions start to reach maturity that they might meet in the middle. Therefore, the framework for action defines exactly that, and the lack of one means there is a likelihood of a lack of common incentivisation and therefore initiatives can and will pull in opposite and competing directions.

The interests of disabled people and poor people may be served by different actions. The needs of poor disabled people might be served by a small subset of both. However, there is no resounding evidence here of both being served. For instance, setting up a National Commission for the representation of disabled people in SL is an action miles away from a commitment to bring water to Dworzark settlement. The former is the mandate of CRPD, while the latter is what is actually needed by the poorest disabled people today.

This chapter indicates that the framework I developed in Chapter 3, now built out with better descriptions against the data points shared, seems to do a decent job of describing DJ in this context. However, this is mainly evidenced by examples of disability **in**justice rather than evidence of DJ. I do not claim it to be a perfect fit, but rather it seems to be in the right space of characterising the key issues found in the study to date.

Importantly too, this chapter has revealed the need to consider the way that preferences adapt in conditions of precarity, given that the claims of people with stigmatised identities for the basic needs of life for all of the community seem to take precedence over DJ claims. This has raised the question of how the expectation of exclusion operates to generate further stigma and self-adaptation. The role of AT in this process of justice claims making becomes vital.

7.11 Conclusion

The commonality of justice claims among disabled and non-disabled people living in urban poverty, and their priority of importance in both settlements, allow to confirm, based on the data, that in this context, with conditions of precarity and misrecognition, disabled people seeking justice may claim for basic needs first, before articulating their claims for rights as disabled people. This is despite DJ being valued.

The framework for DJ I developed in Chapter 3 has been enhanced by further characteristics and seems to fit the data well, but these DJ aspirations emerge somewhat in relief, as they do not have many tangible data points in reality.

It will take clarity of an intentional approach, re-doubled commitment, a shift in who controls and receives investment, and a long time at the current rate of progress, to see the outcomes of disability inclusion and human justice reaching the desirable end game – the inclusion of all people. In the short-term, interventions without proper alignment to an operational understanding of justice could lead to the proliferation of action, advocacy, actors and assets towards each aim. Without a common anchor, these activities may further diverge over time.

As Chapter 8 will now highlight, AT has a pivotal role to play, both in terms of delivery and claiming for justice.

7.12 Summary of findings in this chapter

- H: Global policy frameworks for disability inclusion are based on CRPD; they are strategic but difficult to operationalise. No common disability justice frame is held (7.2-7.3);

- I: Relatively strong ‘disability equality’ legislation nationally favours a paternalistic model of justice. It is poorly implemented in practise with limited recourse to justice for poor disabled people in reality; Government ‘capture’ of scrutiny bodies such as the National Council of Disabled People (7.4);
- J: Willingness of community-based organisations of the urban poor to locally address disability justice in creative ways despite lack of resources. Some evidence of early impact (7.5);
- K: Representation, Recognition, Redistribution all relevant and valued aspects of justice for urban poor disabled people (7.6-7.8);
- L: Those urban poor disabled people organised collectively, evidence some recourse to justice through human rights instruments, not accessed by those in mainstream settlements (7.6-7.8);
- M: Many of the primary claims of poor disabled people are for the basic provisions of life, in common with their nondisabled peers. For those living in urban poverty, precarity functions to side-line disability issues due to the life and death nature of access to the basic necessities of life – water, shelter, food (7.9);
- N: A disconnect at all levels – global, national, local – between those fighting for disability justice and those fighting for poverty alleviation often results in exclusion of poor disabled people from both (7.10);
- O: The failure of the DJ claims to connect with justice for the urban poor (7.10).

8 Relationship between DJ and AT

8.1 Introduction

This chapter explores more deeply the relationship between AT and DJ which the data reveals, building on the themes that have arisen from the first two empirical chapters. Here I reflect on the broader understanding of AT presented in Chapter 6. Chapter 6 also raised the need to focus on 'the why?' of AT. This chapter now considers the relationship between the two according to the four elements of DJ defined in Chapter 7: economic (redistribution), cultural (recognition), political (representation) and disability-specific (disability relations). Negative correlations between AT and DJ, as well as positive, are drawn out within each subsection. Towards the end of the chapter a discussion about the relationship is explored through synthesising the findings in context before I conclude.

8.2 AT and Representation

8.2.1 AT enabling representation

Perhaps the most obvious role of AT is to enable the participation of poor disabled people in activities they choose and value, which improve their wellbeing and quality of life. One international expert summarised what many others also highlighted, perfectly:

> *"AT helps disabled people make independent choices which means that if they want to participate in community or civic matters they are empowered to make that decision because they are in a position to participate. If you don't have AT you don't have the option to even decide whether you want to participate. You don't even have the ability to make those decisions."* (D-02)

Formal participation was valued and strategically enabled by AT. Here, in its most basic form, AT might include a wheelchair used to enable mobility for an event, a hearing aid needed to participate in a community meeting, a pair of glasses to enable reading of a pamphlet or poster, a mobile phone and app to give audible directions to a location. Despite the lack of assistive products available to many slum dwellers in Freetown (as shown in Chapter 6), AT was still universally understood as necessary to aid this participation. As noted in our paper (Austin et al., 2021a) what is being evidenced here is shown somewhat in relief, an impression of the space where participation would be if AT was available. The paper concluded that a lack of access to AT was a significant limiting factor in the political participation of disabled slum dwellers in Freetown. However, it was not sufficient alone to enable full participation due other barriers such as attitudinal (stigma) and physical barriers (access). The paper ends:

> *"Although appropriate AT is almost entirely absent, it remains an important mediator of access to both formal and informal citizenship participation for persons with disabilities who live in informal settlements in Freetown, SL. Further, citizenship participation was valued as a means toward achieving a better future."* (ibid, p.24)

In this study, we have also seen that for disabled slum dwellers in the mainstream settlements, there was usually a limit to participation in formal political process which stopped at voting. However, for most slum dwellers, engagement in the activities of daily life, from accessing water, health or education services, to purchasing AT, is often informally governed, rather than governed under the jurisdiction of the formal structures of the state. The next section delves a little further into the issues associated with informal participation.

8.2.2 AT supporting informal representation of poor disabled people

When asked how change was made in the community, almost all participants from Thompson Bay and Dworzark referred to the informal community structures. In Dworzark and Thompson Bay settlements, as well as in the HEPPO settlement, informal governance arrangements recognised a Chair and Chairlady (sic) as the leaders. In the larger settlements, religious leaders, tribal leaders and community-based organisation are also organised to support day to day activities and decision making. The image in Figure 19, in Chapter 5, showed the 'rules' in HEPPO set by the Chair and Chairlady. As also mentioned, the Federation of the Urban and Rural Poor (FEDURP) and a Slum Dwellers International Affiliate organisation, are organised collectively as described in Chapter 2 – through savings groups, community meetings, knowledge exchange and advocacy. However, disabled people were almost always excluded in the mainstream settlements before AT2030. Without access to AT, many disabled people in the case study could not easily engage in activities outside of the home at all.

When asked about representation before the AT2030 project, local participants in the study reported only one incidence of being engaged in collective community activities or involvement in community discussions. Usually they felt they were excluded:

> *"We do not have the opportunity to discuss our issues as disabled people in these meetings . . . they only consider the non-disabled."* (A-TB-02)

The one person that had been included, did have AT, and was a teacher in the local school and well-respected Scout Leader, something he noted helped him overcome the negative association of disability identity. Yet still, he did not feel able to raise issues of concern about disability; it had not occurred to him this was possible to do so in the meetings he attended. The other participants were not included because they could not access them. The response from these participants was common:

> *"[Interviewer: why don't you go to community meetings, where you say decisions are made?]. Because of physical barriers and challenges."* (A-D-07)

There was also a notable gender bias to participation (and access to AT), though this did not directly relate as much to the FEDURP meetings where women often led the savings groups.

> *"The community meeting is only for men and also stakeholders (leaders) in the community."* (A-TB-05)

One of the reasons cited for not being able to participate, aside from the physical barriers, was the lack of AT. This was clear, and factored significantly, but not exclusively – stigma, attitudinal barriers and the expectation of exclusion presented in Chapter 7 also made a difference. The lack of participation due to 'physical barriers and challenges' was compounded by the lack of collective participation with other disabled people in the mainstream settlements. There were no instances of disabled people in the 'mainstream' settlements meeting together as a group recorded before AT2030, and therefore – as one participant described it – no unity when trying to address problems faced by disabled people.

> *"[Interviewer: how can you address issues of concern to you?]*
>
> *Firstly, we can go to the Chief because he is the head of the community…But when we want to discuss these issues, we should have unity among us [disabled people] so that we will later channel these issues to the Stakeholders [leaders] in the community and call them into community meeting. But there is no unity."* (A-D-01)

This lack of unity did not refer to disquiet or contested opinion, but rather to invisibility and a lack of recognition of other disabled people or any form of collective action. This will be explored more in the next section on recognition, but of course, stage 1 of being able to see representation, is being able to participate – either formally or informally, yet the fact that participants struggled to meet because of the lack of access to AT and poor physical conditions was very clear and present.

The role of representation – community leadership - was the very first success factor in the London 2012 Disability Inclusion model (Austin et al., 2021b); the authors found that without this representation by senior disabled people, sub-optimal outcomes would likely result. This goes to underline the central function of AT in delivering the core justice principle of representation for disabled people at all levels.

Additionally, the data highlighted that collective participation is something many of the slum dwellers interviewed had come to identify as necessary for better futures:

> *"It will be good for disabled people to organize and come together and form a group because in that group you will be able to say the challenges you are going through, some of the struggles, be able to explain to others and other are able to proffer a solution to those challenges. By those discussions also you will be able to inform exciting opportunities that are available elsewhere."* (A- D-05)

AT was necessary for this, as one AT expert mentioned, AT would not be sufficient alone to enable this representation:

> *"Less access [to AT] does affect and mediate. It is a medium for justice; for attending meetings, for going to school and work, living full lives. But we can't think about AT in a vacuum it needs to be connected to these wider aspirations. It's 'for' [to enable] something – it's a medium. You can give a wheelchair but it needs to be connected to something – how can that person have a voice?"* (D-05)

Without any AT, I conclude, representation is not possible for most. It was a necessary, if not a sufficient factor in describing the lack of representation. I will go on to develop this argument more in the context of the idea of transitional demands, later, and the other factors which mediate justice will be discussed below. However, before moving on, it is necessary to consider the potential for negative impact of AT on representation.

8.2.3 AT hindering representation of poor disabled people?

There is no evidence from the study that AT might hinder the representation of disabled people, if it is of good quality, readily available and well used. However, if AT is considered to be the only necessary intervention to aid the representation of disabled people, it could 'crowd out' the need to do proper work to tackle other barriers such as attitude or stigma, as this quote from a prominent international disability expert suggests:

> *"Some aspects of AT may fall into a medical model category that looks at fixing persons with disabilities as if there is something wrong with their bodies… Techie nerds want to solve engineering problems and they don't have a discourse on human rights. There is a danger this may add to stigma on the premiss that our bodies are broken."* (E08)

This stigma is related to this idea presented in Chapter 7 on stigma. Essentially, while it is pragmatic to provide support in the form of AT, this cannot be at the cost of assuming 'normalisation' of bodies that are different. Similarly, there are some disabled people who can engage 'as normal' with AT, but they are not everyone. Those with more complex impairments and needs must still be enabled to participate as the disability relations element reminds us.

Some evidence from international experts suggested that AT at the forefront of tech development, can actually reinforce ableism. Talking about the development of exoskeletons, a technology designed to enable wheelchair users to walk, one international leaders said:

> *"What is so dramatically important about walking very slowly and uncomfortably? Its ableism. It's exactly what AT does wrong, because it has to be exciting and futuristic and sexy. It doesn't deal with the real needs of real people."* (D-09)

Of course, no one has an exoskeleton in SL. But this relates to the debate about 'normalisation' as a means to inclusion (Moser, 2000). Put simply, this relates to the expectation that, for instance, wheelchair users should aim to be ambulant as it is 'normal'. This point was raised by a Global North leader. Yet, in the Global South context one must be mindful that these debates feel theoretical and not very practical. I have seen in the wider work I do in SL, that people choose non-functional, white prosthetic arms, which are heavy and cumbersome, rather than the new type of prosthetic which does not look like an arm at all but functions well to write and do actions. This relates back to the point about stigma, and the theoretical debates between AT provision and the disability movement which wants to reject functional limitation as the basis for intervention.

Another issue with technology for representation relates to a more mainstream point. If it is assumed that technology can – unchecked - open up channels of communication for disabled people through social networks and campaigns such as Milan (Milan, 2013) speaks of, this is not in keeping with the reality of tech access, connectivity and the ownership of the platforms which control this communication. Bringing into question the ownership of these technologies, and the limits to the freedom they offer takes us back to a discussion about the neo-liberal backdrop to the provision and use of all technology. I will return to this point. While for sure mainstream technology for communication does have the power to offer some potential for collective action, information sharing and organising, I suggest it must be treated with caution. Nevertheless, it is relevant, that digital communication must be accessible to disabled people:

> *"Disabled People are facing an information access barrier – if any person doesn't know it is their right to participation on civic matters, they don't think they can. The channels that are used to deliver this communication are usually not going to be accessible - so they are blocked from engagement."* (D-02)

Further, representation of disabled people involves more than the simple presence of one or two disabled humans in any setting, be it digital or physical:

> *"Involving disabled people is necessarily disruptive; challenging the hegemony and assumed ways of doing things. But it is not unproblematic – the assumption that because you are a person with a disability you might know the best thing for you, and for others, doesn't hold."* (D-6)

In sum, this data shows that taking account of other issues is essential, but AT remains vital and necessary:

> *"[Disability Justice] requires AT to get there, but it's not only about the AT, it's also about other factors, but the AT is a prerequisite, but there are lots of other issues too - like you might not have been to school or know that your voice is valid and be listed to."* (D-3)

With these caveats, AT can be viewed as necessary to aid representation and indeed as a key strategic element in doing so, albeit not a sufficient element alone. Certainly, it is not the case that we can assume that AT equals representation, ergo political mobility and traction. In other words, we cannot necessarily translate representation into political mobility. This is something to be explored further. Yet, for sure, without AT, representation will be unlikely and will render political mobility nearly impossible. It seems that **AT is a necessary if not a sufficient factor in representation**. Now recognition is considered.

8.2.4 Returning to the description of AT in relation to representational element of DJ

Now returning to the role of AT in representation, I offer the following loose characterisation:

AT enabling the representation *of disabled slum dwellers in the political processes, debates and struggles they wish to prioritise; both formal and informal. AT supporting the avoidance of misrepresentation*

This will be considered further in Chapter 9, and is but the starting point for further research, but it provides an overview of the way that AT has factored in terms of representation in the data I collected. Now I turn to recognition.

8.3 AT used to enable Recognition

In the sub-sections below, I now present the themes emerging from the data around the role of AT in terms of recognition of poor disabled people in the context of the study. Before diving in, it is helpful to note that this aspect was not anticipated to be quite as strong as the data indicates. Being recognised and validated, even through asking about AT not even getting it, seems to have an impact. This relates directly to the nature of disability identity in SL, which is explored first.

8.3.1 AT as a mechanism for Recognition: being seen and feeling valued

It is helpful to first build a picture of the reality of how disability identity has been shown in the data to enhance the theoretical context set out in Chapter 4. One finding was that while SL has a fairly strong policy framework on disability, this is poorly implemented in practice, as mentioned in Chapter 6. The quote below was common from slum dwellers interviewed. This man was talking about his right to free healthcare as a disabled person, but the same was true of the free education promised:

> *“ . . . it is in the Disability Act . . . . but it doesn’t happen. So, when you go to medical (people) you have to pay. They request you to pay . . . . We are not getting some of the facilities we are expecting as citizens of SL.”* (A-D-05)

The evidence suggests that the experience of being a poor disabled person in Freetown often means living with disappointment of broken promises and commitments made in policy not coming to fruition. Leaders of the HEPPO community made this point perfectly:

> *“In SL, we have a Disability Act, which talks about our rights, and mobility, and AT …but the problem we have is that our policies are just like book; when they have written it they don’t act on it. They know nothing about issues of disability….that is why I think we are not recognised in terms of getting the facility that we need…. To govt of SL, the one thing I would say is that the Disability Act is not enough on your desk.”* (E-01)

As the participant noted “[they] are not recognised.” One expert commented on the type of recognition that was hoped for disabled people in SL, and what was felt instead:

> *“A lot of the time when you talk about inclusion you are saying ‘equal opportunity’ not an advantage…inclusion means (disabled people) deserve to interact in society across social, economic, or health access, like everyone else, and when this is not provide it leads to injustice.”* (D-2)

Thus, formal (positive) recognition is lacking, and the data also suggests that in reality, despite legislation, disabled people’s lives are often offered less value than others, in day to day settings:

> *“[When I had to have my leg amputation] at the Government hospital they gossiped, they said, “this girl may die, and that’s ok”. I was so depressed and sad and I couldn’t keep myself calm . . . . the non-disabled people should stop mocking the disabled people in this community because of their condition.”* (A-TB-1)

This was a harsh but typical example of how disability identity is stigmatised. Though it did vary given the context, in the mainstream settlements stigma was rife:

> *“So, you can go around [to meetings, etc.] but you choose not to because of the stigmatisations you get from people.”* (A- D-01)

This again relates to the idea of exclusion, shame and stigma raised in Chapter 7. Furthermore, AT in the data was much more than an aid to functioning as one international expert who worked in SL mentioned:

> *“[REDACTED name] was so very proud of the fact that his son had got him a wheelchair and [REDACTED name] with her crutches…. because there were so few products, those that did have AT (especially the more sophisticated AT like*

> *wheelchairs or crutches) felt like it was a recognition as well as helpful practically. It felt like a really positive thing; what it meant to people to get AT."* (D-05)

The wheelchair in question had no function and did not wheel. When asked directly about access to AT slum dwellers often referred to being seen and being recognised, not just being able to physically access meetings due to AT. For instance, representatives from the HEPPO settlement, where they had over 70% AT coverage, said:

> *"With AT we can move to meetings. We can interact with different people; stakeholders and the committee will recognise us."* (E-1)

The role of AT was linked not just to what it could enable someone to do, but what it could enable them to be, overcoming, to some degree, the stigma and exclusion. One of the international experts who worked closely with the local research team on the AT2030 project in Sierra Leone for a short time summarised this really well:

> *"At the start [of the AT2030 project] when we went into in an informal settlement we started organising workshops with the local teams. Anecdotally, speaking to people in the settlement, one thing that people who had AT felt, was that they could participate. Disabled people who had access to AT, that is. It was like a status thing. Disabled people in general were so invisible, so the fact they had AT meant that someone had recognised that they exist and had a difficultly. Being able to access to crutches gives status and being recognised as a disabled person was important." (D-06)*

Her key point is that "it was a status thing". Beyond its usability, it was highlighted that AT is part of that stigma story, as this expert mentioned:

> *"The legitimisation of participation, the structural shift, is important - the technology can enable you to go to the meeting but you might still be 'in-valid' … you might not have an authentic platform if stigma still prevents participation…you need more than the tech, but also a legitime platform."* (D-06)

Here we see the role of stigma in devaluing the presence of a person, if even they are able to gain access and entry to a meeting. The stigma within those who are unable to accept the AT user is automatic, there is a lack of critical analysis, only a simple binary decision that the person is not a valid part of the event. This is in keeping with the brief discussion on stigma and internalised oppression people can face when belonging to a marginalised group (Section 2.27). Again, we see it is important to think about AT as part of a broader mechanism for being valued and feeling seen. One of the key findings of this study, which was not anticipated, was that AT had a role beyond functional enhancement, beyond the 'doing', to the core of what it is to be recognised according to who you are, to the 'being' of someone. By allocating AT, or even by asking people questions about the AT they needed, there was a recognition and validation of a disability identity in a new light. This was explained by the participants at a workshop on the 'mainstream' settlements on Disability Day 2019 (the first time it had been recognised in the settlement – which made the front page of the paper in Freetown).

> *"Before [AT2030] I was ashamed of my visual impairment, but since this project has started, I now have the courage to speak, express myself and move around the community."* (B-DD-TB-19)

If AT is 'for' more than a support to functioning, if it is also needed for recognition, this brings to light a new angle on AT provision. As one expert commented:

> *"There is an assumption in the RATA that the Ministry of Health should deliver AT formally [because]…it's is important for overall health – that's what it's for. But I would like to change the order and say that AT is for something you want in your life – so if we understand what people want AT for, in their lives it might be a more efficient use of resources".* (D-05)

Following this logic is further cause to understand the 'why' of AT, and recognition is a part of that story: ***AT to be seen*, *AT to be heard*, *AT to be oneself*.**

Some interviewed, go so far as to suggest AT should not be viewed as out of context from what it is 'for' as this significant global leader and activist explains:

> *"AT is hard to portray as a stand-alone thing, because AT, as a wider understanding of technology which is assistance is not a stand alone thing but a reasonable accommodation - what is AT for education?; what is AT for health?; what is AT for sports recreation and cultural participation?; what is AT for women's rights and reproduction? So the challenges and debates and advancements… it would be more counter intuitive to view AT as a stand-alone thing."* (D-08)

Succinctly put*, "global policies need to be linked to outcomes of wellbeing or of general participation"*(D-05), as has already been seen in the earlier chapters.

Now the potential for negative consequences of recognition through AT use is considered.

8.3.2 AT as reinforcement to misrecognition?

The main elements of the data here, related to who makes AT and who decides what AT is needed. The answer to first question is largely non-disabled people, to the second non-disabled people from the Global North. As one African expert commented:

> *"More work should be done in conjunction with local people and led by local people. Even if initiatives cannot be entirely handed over to local people – the people on the ground should be local people. We need to demonstrate that there are skilful people in Global South that are not corrupt and are interested in helping local communities to have access. Not just coming with knowledge e.g the medical profession is prescribing to disabled people 'we've studied you and we know the answer' – we should rely less on ex-pats."* (D-4)

This is not at all unfounded, in my experience – the AT sector leadership consists of almost entirely the Global North (usually non-disabled) leaders. AT is largely made in the Global North as the product narratives set out in Chapter 6. The barriers to accessing the Global South markets, in the language of the Global North companies that see them as 'emerging', are many and varied, with significant exclusion of disabled people from the process. The need to tackle the exclusion of disabled people from the AT design (and manufacture) process is highlighted in AT2030 innovation work, and particularly in the Disability Interactions Manifesto (Holloway, 2019) which makes the case for this. Importantly, some authors have suggested that misplaced hope can reinforce misrecognition of the idea that technology can solve all the problematical aspects of disability, especially where no account is taken of the wider support systems needed (Roulstone, 2016). However, I propose that viewing technology against a frame of DJ helps to alleviate this type of misrecognition and exaggerated understanding of the role of AT as such. Nonetheless it is important to hold these potential impacts in mind as we move to characterise the role of AT in DJ.

8.3.3 Returning to the description of AT in relation to DJ recognition

Returning now to the characterisation of AT's role in the recognition element of DJ, I offer the following enhanced wording:

AT enabling positive recognition of disability identity *for individuals and collectively, in the context of intersectional humanity. AT supporting the avoidance of invisibility and misrecognition.*

Again, this characterises the data and evidence but is also simply a starting point for further investigation. Now I move to consider redistribution.

8.4 AT used to enable Redistribution

In this subsection we look at evidence about the role of AT in redistribution for poor disabled people.

8.4.1 Disability and Poverty; economic exclusion reinforced by lack of AT access.

It is well documented in Chapter 2, that disability and poverty are inter-linked, and the evidence suggests AT is a part of that dynamic since the mutually reinforcing nature of poverty and disability is exacerbated by, and exacerbates, a lack of AT access. One of international expert described this well, from her considerable experience:

> *"If you have a disability you are more likely to be poor and vice versa, so I would expect that the poorer you are the harder it is to access AT because of the cost, because of the environment, being able to actually source it, and I would expect that AT is more common in urban areas in most countries than rural areas (where its pretty unlikely, if you are poor). The poorer you are the higher your costs (of life), on healthcare, and travel, all your basic needs, so your likelihood of purchasing AT is less than if you were even slightly richer."* (D-7)

Participants from this study, corroborated this point and that presented in the literature review, suggesting that AT has an important role to play in terms of increasing the economic participation of disabled people that need it, and that this is considered of immense value:

> *"The technology helps me greatly because without it I can't go anywhere, within and outside the community … even though its painful [his prosthetic is from 2007] I can go many places. It helps me to get money. The business I am currently doing, I wouldn't be able to have that without the technology [prosthetic]. I wouldn't be able*

> *to hold the crutch and have the bag on my back. I am doing a micro savings business."* (E-02)

This type of language around economic participation is commonplace across the global policy arena, as summarised in the WHO GREAT summit consultation (D-GREAT):

It is also central to the new AT policy for Sierra Leone, which states in its forward section (and advocates throughout):

> *"AT can enable people with difficulties in functioning to live healthy, productive, independent, and dignified lives, participating in education, the labour market, and social life, thus contributing to the nation's growth. Timely access to appropriate AT can reduce the burden on already stretched formal health and support services."* (C-ATP)

It is certainly not the place of this research to proffer critique on such a commitment by a national government of a very low-income Global South country wishing to enable access to livelihoods for disabled people using AT. However, it is worth dwelling for a moment on what 'access to livelihoods' actually means in practice for poor disabled people – given that the narrative is strong through all of the data.

Access to employment, education and income was raised by most of the interviewees (slum dwellers, national stakeholders, and international experts alike). A standard comment was thus:

> *"Without my AT I can't do business without relying on someone, I can't collect my daughter. With my AT I can go to my job. Without my AT I am nothing."* (E-1)

"Without my AT I am nothing" (E-1) is such a strong statement representing the impact of AT on exclusion from participation.

Younger disabled slum dwellers also mentioned the need for AT to access education in order to get a job in the future:

> *"For me I can say with my crutches I can move and go to class on a [motorbike] taxi, I can be more expert because so many people think that disabled people are not educated."* (E-03)

But there are also some specific aspects to consider here.

8.4.2 'Uncomfortable' dynamics: AT and Begging

That AT supports access to livelihoods is not a unique finding of this research, but usually when economic participation is referenced to by global or national policies this refers to access to work or business. But the nuances of the interaction with extreme poverty is valuable to consider and makes uncomfortable reading for those that want neat solutions to messy global problems.

Evidence of the link between AT and use of begging came through quite strongly in the data. One international expert talked about his experience growing up in a West African country, where he, personally, had access to education and AT, but saw a number of other disabled people begging as the only possible form of income:

> *"In my country [REDACTED], the chance of participating is premised on which family you were born into…I started school at 6 and became a Professional [REDACTED]. From the age of 11 I was able to access healthcare at the University Hospital of [City, REDACTED] and in the UK. But there are so many other disabled people born into really poor families. Beggars in my country are organised…you have to pay a fee to the overlord. We tried to organise a meeting of the community of disabled beggars, but beggars were not involved in our campaigns at all. We used to have an outreach programme and tried to give them (donated) wheelchairs once a year, but the disabled beggars had no education and no skills. Sometimes their families made them beg to support the rest of the family."* (D-04)

Begging was also noted in SL by disabled slum dwellers in the study as necessary to get by. This chimes with the work of Groce *et al.* (2014) which considered the role of begging as an overlooked issue around disability and poverty. The authors noted that while disabled beggars are visible on the church steps, marketplaces, and at intersections in most cities around the world, there is a dearth of contemporary literature about their existence. They suggested this may reflect some cultural aspects as people assume disability and begging are inevitably linked, which has some viability given the association between disability and poverty. However, the authors reported that begging remains a very urban issue, with tolerance linked to perception of deserving and undeserving poor (Stone, 1984, cited in Groce, year, pp.2-14). Ultimately, they highlighted that people decide to beg due to lack of other options, internalised stigma, lack of education and limited employment prospects, and a downward spiral of poverty. There is also reported a terrible trend of forced begging and intentional maiming (ibid.). The work, based on evidence from East Africa, ultimately identified the need to provide alternatives to begging which people can choose to undertake.

AT in SL was often a part of the begging process, used to identify disability as well as to enable mobility; in fact, the HEPPO settlement was made up of people who formed a street begging community. The relationship between begging (literally calling on strangers to donate out of pity) and the attitude and approach of organisations of the urban poor looking to overcome the stigma afforded to poor people (overcoming pity) is interesting. One of the core principles of the SDI federation is that poverty is not powerlessness, and this is actually one of the slogans painted on the wall in the settlement (shown in Figure 21 below) and chanted at most meetings.

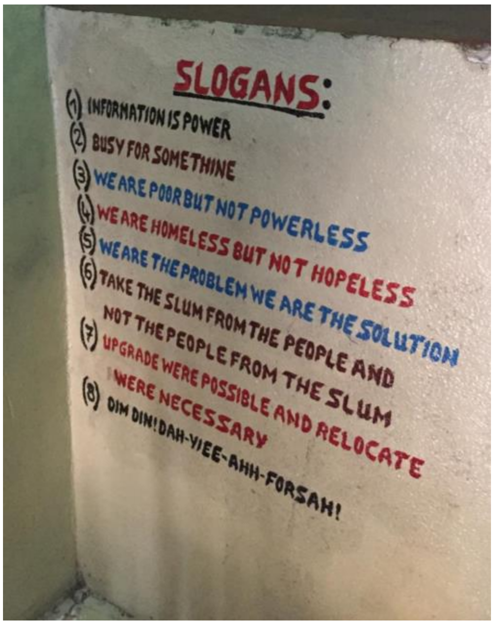


Figure 22 Slogans of FEDURP written on their wall

However, for many extremely poor disabled people it seems the generation of pity is a necessary first step to survival and a part of everyday life. When this study first began, this reality was revealed as a little uncomfortable to the leaders of the organisations of the urban poor who work incredibly hard in their own time, every day, completely unpaid, to overcome the stigma of pity and a low self-image (related to poverty not disability in this case) as Appadurai described (Arjun Appadurai, 2004).

One of the stakeholder organisations did attempt to organise the disabled street beggars in Freetown into savings groups (more in line with the SDI approach and model). However, this did not work (largely because savings groups are predicated on the trust generated through the proximity of permanent neighbours, and some degree of steady income). The stakeholder said:

> *"We noticed that there were a lot of disabled beggars that came together the beg in the central street. One key challenge we encountered was that they met at a particular point, at a time, but they were coming from [living in] different areas in the city. Our approach in terms of mobilising savings groups has to do with geographical proximity in terms of communities which makes it easier to mobilise and speak with one voice towards a common aim. With them coming from different locations …it becomes very much more difficult to establish a savings group because…they do not have a stable place. Coming together is a key pillar to advocacy…'united they are' [and] stronger they will influence policies to…make the change they deserve. So that is the message we are taking to them now."* (A-S-01)

This goes some way to explaining the separation between Organisations of the Urban Poor (OUP) and DPOs, and is perhaps also part of the reason why the literature on urban poverty does not treat disability in quite the same way as any other identity-based exclusion. This uncomfortable narrative around begging does not support empowerment in the traditional understanding.

When considering the question 'AT for what?', one of the answers the data gives is that AT is used for begging, and this is something which is valued. This does not feature in national, international or donor policy documents, yet it is an uncomfortable reality. Does this enablement really enhance justice? This is a very pertinent question. It is helpful to visit the other end of the spectrum – AT for entrepreneurship, which certainly does grace the covers of many development project annual reports.

8.4.3 AT, entrepreneurship and Innovation

One of the international experts interviewed also runs an African accelerator. At the time of interview (July 2021), he shared that he had supported 22 AT innovators (usually disabled people themselves) to develop AT products, as he said: '*all with African innovators, some have gone to market and taken solutions to people'* (D-2). When interviewed this leader was passionate about the role of entrepreneurship in increasing access to AT:

> *"The start-ups [in the AT accelerator in Africa] I have been able to do (gets AT to people). Entrepreneurship makes this reality come sooner… we either wait a long time before other players catch up, or just keep doing things the way they always have. Entrepreneurs build solutions for a purpose, that users love, and what we have seen through our work is a lot of effort goes in to testing the solutions that work – using the feedback to improve the products."* (D-2)

To this extent AT both enables innovation and innovation enables AT access. The products supported through this accelerator also confirm the boarder definition of AT I suggested in Chapter 6, as many products are digital and more mainstream than targeted (anon[7], year). It is also something that was being discussed in SL, as was revealed in the last discussion with the community leader for Dworzark and Thompson Bay. He shared:

> *"Before, they [disabled people living in the settlement] had a fixed concept of what they think they need e.g. crutch and they won't use anything else. Now, people are recreating and innovating things. Designing something more comfortable themselves. If I don't have money to use wheelchair, they ask, how else can I reach to the location? We have carpenters in our communities who can make things."* (E-04)

It must be stated that this perhaps raises as many questions (about quality and clinical guidelines) as it answers in terms of access to good quality AT, and this should not be read as a recommendation or a condemnation in the latter case. However, both data points highlight a belief that community led innovation, e.g., the community doing things for itself, usually in lieu of other help, is viewed as necessary as it reinforces the notion that AT is essential for overturning the lack of representation of AT user in AT design and production. As one of the experts summarised:

> *"How do we quickly demonstrate that PwDs (sic) with AT can actually lead independent meaningful and productive lives? … the way you can do that fastest, is to get AT in their hands."* (D-2)

---

[7] the reference link here is shown as anon to protect the confidentiality of the speaker

If demonstration of productivity and innovation – cool aid entrepreneurship – attracts funding (and it does!) then two matters should be investigated further, (1) the role of AT in undertaking what is necessary to overthrow connotations of stigma and societal disapproval of disability identity, and (2) whether AT for participation in the existing labour market-which is exploitative - actually help, or hinder.

8.4.3.1 AT reinforcing notions of exclusion and the reification of productivity

When Fraser described redistribution, she was not simply talking about access to jobs within the existing economic constructs of society for one or more excluded groups. She was referring to the need to (1) identify and name, and (2) challenge and overturn the nature of the economic structures which keep such exclusion in place, as set out in Chapter 2, alongside the DJ framework in Chapter 3. A true questioning must go beyond seeking to know how AT helps disabled people to access more jobs on the same (bad) terms as other exploited people; rather I am called to attempt to understand how disabled people can also be fully included in the struggles to build a new system. If AT is enabling disabled people to participate in an economic system that continues to exploit the many, for the benefit of the few, this is a fundamental issue that cannot be ignored.

I have mentioned before the need to avoid assumptions that productivity is best whatever the consequences and offered a critique of this ‘productivism’ (Mladenov, 2015c). Where AT is used simply as an enablement to productive activity or assumed to be only for the use of such, it could be harmful to DJ. What might be helpful here, is a distinction between what is necessary for individual survival – AT for work within the existing system, versus the strategic demands of DJ which may require a fundamental reassessment of that system. I will use this complexity to shape the discussion in Chapter 9.

8.4.4 Returning to describe relationship between AT and Redistribution DJ

Returning now to the characterisation of the relationship between AT and Redistribution Justice, I offer the following additional descriptor:

***Redistribution** – AT enabling redistribution both in terms of access to ‘wealth/assets’ and claims-making toward such. AT supporting the avoidance of maldistribution*

I now move on to look at disability relations, encompassing disability inclusion, intersectionality, solidarity and relations between disabled and non-disabled groups.

8.5 AT used to enable Disability Relations

I set out in Chapter 3 that disability relations took those elements of the Sins Invalid’ framework which were not well captured by Fraser, and I specifically highlighted these four elements, which I now come to in turn.

8.5.1 AT and radical inclusion

In the data it is not so much that AT enabled radical inclusion, as no radical inclusion was found either in the SL setting or in examples given by the international experts. However, radical exclusion was precipitated and made worse by the lack of AT. I think it has been shown already that access to all forms of participation was made harder by a lack of AT, and campaigning for change and rights was also made harder or impossible. The lack of AT is noted as disabling this type of participation over and over again in the evidence already presented.

8.5.2 AT and intersectionality

The recognition of intersectionality was limited in the data I collected. I did not disaggregate most of my data because of the small numbers of people, and though I attempted a gender breakdown that was equal in the participants I directly interviewed (data sets A, D, and E); there were not many instances of intersectionality issues reported and so I must say the evidence against this point is weak.

However, in terms of the RATA survey, it found women had less access to less expensive AT than men (Ossul-Vemehren et al., 2022) and in terms of the participation of women, I found that women had even less chance to participate in community meetings as shown already. In one case, older people who have more status in the community commanded more respect and the stigma of disability was somewhat overcome. This was reported by two men who had had roles in the community as spiritual leaders and hence were afforded help that other disabled people did not receive. However, this element of consideration does need more investigation in future work.

8.5.3 AT and solidarity

To summarise the evidence on solidarity, the obvious point about participation in collective action has already been made. However, interestingly the data also suggested that there was a huge disconnect between disability organisations and organisation of the urban poor. In this case AT not only functioned to practically make those connections harder; the disabled people from the mainstream settlement were unable to get to the meetings of SLUDI in the center of town, with the disabled people without AT (mainly in the mainstream settlements) not feeling part of or connected to the mainstream disability movement. This was not the case for HEPPO registered as an NGO and very much a part of the SL disability movement. HEPPO inhabitants also had AT, which enabled them to get around. It is perhaps a little too strong to suggest that it is possible to conclude it causally, but certainly people without AT were not able to organise and participate collectively with disabled people, nor were they able to participate collectively with non-disabled people in organisations of the urban poor without those organisations considering more inclusive approaches. Even then, without AT, participation was hard and limited.

8.5.4 AT and disabling relations

It is worth considering whether stigma was associated to AT. This is something I expected to find – that those who use AT are being looked down upon or judged poorly because of their AT use. I actually did not find any instances of this, directly in the data. However, at least the disabling relationality, or treating disabled people less favourably, has been often found and is well rehearsed in this text. One of the surprising findings was that relations between disabled and non-disabled people were perhaps, improved in some cases where disabled people felt recognised with questions validating their need for AT (as reported in Chapter 7).

This was a surprising finding. In my experience in other countries there are many examples of stigma related to AT, but perhaps because of its abject lack, and obvious need, that was not the case here.

8.5.5 Returning to the definition of AT enabling disability relations justice

This element is somewhat different from the others as it draws out specifically the need to engage between disability and non-disability movements. It really goes to underline the value of Fraser's understanding of bivalent collectives located in the middle of the spectrum; they are differentiated by political-economic-cultural elements of Fraser's definition, and their injustices are traceable to all of these too. Fraser claimed gender and race are bivalent collectives, who may suffer socioeconomic maldistribution and cultural misrecognition (Fraser, 1997), and I suggest disability too implicates all aspects of this framing. Here I have set it as a separate element as the data showed so many instances of specificity related to disability, though in a truly inclusive future this may not be necessary.

As before, given the debates I now return to the consideration of disability relations as an additional characteristic of this element of disability justice, given the evidence:

Disability Relations - *AT enabling collective access; cross-disability solidarity, recognising interdependence, promoting an intersectional participation; AT supporting cross-movement organising (both within disability and between disability and other justice movements). AT enabling strategic participation.*

8.6 Discussion: the relationship between AT and DJ

8.6.1 Developing a model of DJ within the context for precarity

Perhaps most clearly the relationship between AT and DJ is summed up in the following quote:

> *"I don't feel AT is valid as a goal in and of itself, any more than any other technology – it's what they allow you to do. There is a much greater blurring now… 'norming' of access to smart phones… it has to be a rights-based thing… the kernel of the whole approach is the model that's used …and on the daily basis…for instance the wrong model with the wrong aim could be harming disability justice by using an understanding that people should be lucky and grateful to receive AT."* (D-06)

This was reinforced throughout the study, with the need to link AT to outcomes of life:

> *"Global policies need to be linked to outcomes of wellbeing or of general participation." (*D-05)

But this is not a simple thing to do, and AT access is pressing, so no time must be wasted navel gazing. As this expert articulated the progress that has been made so far is not enough, we cannot be stalled:

> *"We must be more ambitions, and more bold, work with more urgency. This [view] sometimes stems from some frustration, there are a lot of people patting each other on the back for accomplishments while we are looking at a large and growing gap. We need to do more to close the gap – the call to action needs to be louder. Some of the events I've been able to participate in – GDS or GREAT – are about mobilising people and agenda setting which is important and good to celebrate. But are we missing a call that is pushing us to go much faster, because the gap is growing faster while we take time to make systemic working a priority."* (D-01)

This summarises perfectly the need for clarity of approach, and a chance for each actor to play their part in supporting AT access, I would suggest, as part of a broader DJ model. This chapter has started to map the characterisation of these different characteristics of DJ and has broadly underlined the need for such a framework which allows for complexity but also for codification. I will discuss this further in Chapter 9, bringing all of the elements together.

8.7 Conclusion

The evidence suggests that AT is necessary but not sufficient along to ensure representation, redistribution, recognition and disability relations.

AT was considered a right, to enable participation:

> *"AT is part of our fundamental rights. It makes us who we are. I am a disabled person. I have accepted that fact. I cannot deny that. But what makes me functional is my AT so I think it's a right, not a privilege."* (E-1)

There is a danger in all areas that AT might be presented as a panacea, negating other, perhaps more structurally ingrained, injustices. As such it is not possible to suggest that AT always, in all ways has a defined positive impact, and in fact poor quality AT or a lack of services around it, and a lack of ownership over decision making and production of AT do appear to be potential hindrances to 'parity of participation' as defined in this study.

8.7.1 Summary of findings in this chapter

P: AT is valued and necessary for all aspects of parity of participation, but not sufficient alone (8.2-8.4);

Q: However, AT is necessary to include disabled people in claims-making toward a better future (8.2-8.4);

R: There is the potential for negative correlations between AT and DJ **if** there is no strong framework for intervention sitting behind AT provision (8.2.8.4);

S: DJ is 'the mission', AT is a mechanism (8.5);

T: Any model of DJ for urban poor people must also be anchored to their struggle against poverty. Without modelling for precarity the model is not relevant to their daily lives and real choices (8.5);

U: Disconnection between DJ and campaigns for poverty alleviation results in 'first steps' action towards each which can pull in opposite directions (8.5);

V: Real issues of balance of effort and sequencing between the two (DJ and Urban Poverty) arise (8.5);

W: AT is nonetheless strategically significant and can be viewed as a transitional demand for poor disabled people both in justice seeking as disabled people and as people living in poverty (8.5).

9 Discussion

9.1 Introduction

In this discussion chapter the evidence presented in the previous empirical chapters will be synthesised and the findings interpreted. A particular focus is offered in terms of contribution to the academic field, but I also make suggestions for practice.

The chapter is organised as follow. Firstly, I provide a reminder of the research questions. Secondly, I summarise and interpret the findings according to the research questions in turn. Thirdly, I explore the resulting concluding themes: (1) AT as the mechanism, DJ as the mission, (2) AT as a transitional demand of DJ, and (3) DJ as part of a wider justice movement. Finally, I set out the limitations of the work and make recommendations. A short conclusion is presented in Chapter 10.

9.2 Revisiting the Research Questions – a recap

For ease of reference, the core research question addressed in this thesis is:

How does access to AT mediate recourse to DJ or urban poor people?

The overarching research question is answered in this study in relation to three sub-questions:

- **RQ1. What is this situation in relation to AT access globally, nationally, and locally? What definition of AT is the best fit for the data?** (the focus of empirical Chapter 6)

- **RQ2. What are the dominant understandings of DJ globally, locally, and nationally? What are the main claims for DJ of urban poor people in the study?** (the focus of empirical Chapter 7)

- **RQ3. What is the relationship between AT and DJ for urban poor disabled people in the stud**y? (the focus of empirical Chapter 8)

This thesis has sought to investigate the role of AT in enabling (or preventing) poor disabled people claiming for DJ, focusing on the experience of urban poverty with a case study of Freetown, Sierra Leone. Building evidence from conversations with slum dwellers, stakeholders, policy and research documents, and combining this with the inputs of international stakeholders leading the global AT agenda, I have revealed a picture of AT access mediating disability claims-making to a significant degree in the preceding chapters. Though the relationship between AT access and recourse to DJ appears as unquestionably causal, the dynamics are complex and intersecting. To build a better picture, three elements were explored: access to and definition of AT (Chapter 6), meaning of, and claims for, DJ (Chapter 7) and relationship between the two (Chapter 8). I will now consider these in turn.

9.3 RQ1: AT access and the definition of AT

9.3.1 Access to AT

In the first empirical chapter I sought to understand access to AT via several means: interviews with slum dwellers and their stakeholders, international policy and trends, a country capacity assessment and informal markets study in SL, international interviews, and a review of the Rapid AT Assessment (RATA) (Ossul-Vemehren et al., 2022) in each of the settlements. The evidence presented suggests that 15% of disabled people globally have access to AT; however, there was no comparable national data to make the comparison between the global and the country level which the AT Country Capacity Assessment (ATA-C) points to as a data point in itself. The picture painted across all three geographical levels revealed significant market failure in the product markets (with efforts to tackle this via markets shaping), the need to strengthen systems to enable provision and to engage in innovation around new and cheaper mechanisms to deliver products and services, a general lack of data (though the GReAT report does now address this to some extent), and an increase in concern to address AT provision by new actors.

At the local level, the evidence revealed that 21% of adult slum dwellers in the mainstream settlements in Freetown (Dworzark and Thompson Bay) self-classified as disabled and their AT access was broadly in line with the international assumptions. Up to 15% of the population reported having access to AT, but most of this access referred to eyeglasses (81%; 52 pairs), and much AT purchased was often found in the informal market (31%). Women and girls had less access (13%) than men and boys (18%). Conversely, in the autonomously run settlement led by disabled people and their families (HEPPO), 48% of adults self-classified as disabled and 71% of those who needed AT had access to at least one device. Here, wheelchairs were the most common (19 of 41 devices found), followed by tricycles (6); most commonly these came from the NGO sector (45%).

We can draw several inferences here. AT access for mainstream slum dwellers is broadly in line with the global picture, although the types of products were less varied by need, and there was a reliance on the informal sector for provision (essentially only the cheapest products accessed via the cheapest route). Anecdotally, there was a focus on low-quality products, for instance the only wheelchair found did not even wheel and was decades old, which implied that the unmet need in the settlements may actually be higher than reported. This should not be read as a de facto rejection of the informal market, which provides a good service in some cases, and might be investigated and supported further in the provision of AT in low-income settings. Instead, this can serve as evidence that more complex, expensive products which require fitting and sundry services are simply not available at all in this low-income context.

As set out in Chapter 8, during COVID-19, a house-to-house food distribution in the mainstream settlements located many, many more disabled people (hidden through lack of access, stigma and shame) than had ever been met by the leaders of those settlements before. Thus, when this is also considered, a likely story of a greater than reported need for AT and a smaller number of fit-to-use products, than the overall 15% figure might imply, can be inferred.

In the HEPPO settlement of collectively organised disabled people, conversely, needs were described as more complex (with many members surviving polio) but AT access was much better. Not only the concentration of people with similar life experiences appeared to aid information sharing, but it also seemed to reduce stigma and invisibility. Leadership by disabled people brought disability issues to the forefront of the community's collective claims. Though all settlement dwellers (mainstream and autonomous) needed better access to housing, utilities, education and health services, using their collective power, HEPPO had registered as a formal NGO and used Human Rights legislation to fight, for instance, against their eviction. HEPPO is part of the DPO network in Freetown and used their advocacy to have a visit from the First Lady, attracting attention to their plight.

HEPPO's members still needed more devices than they had, but their access at over 70% is literally phenomenally surprising for a very low-income community in the sixth poorest country in the world. I have not seen anything like it in the 35 countries we work in for AT2030. We can conclude that there is some form of relationship between the autonomous, collective nature of the community and their ability to win access to AT, but the exact nature of that relationship is still unknown. Current research did not show whether it is the centring of disability issues, or the overturn of stigma, or collective nature of the claims making or, more likely, a combination of all three; thus, this requires further investigation, which I hope to do.

In summary, at local, national and international level the data reveals critical levels of unmet needs, poor quality products, and markets and systems failing to deliver AT for the people who need it. Significantly better access was found in the autonomously run settlement, leading to the conclusion that AT access may be mediated in part by collective action and community leadership, though this requires further investigation.

I will now look at the definition of AT.

9.3.2 Offering a new definition of AT

Remembering that the WHO definition of AT was found to be adopted by most actors, and this priority product plus service model was what I tested the evidence against. Findings presented in Chapter 6 highlighted that the current definition of AT is inadequate because it is inexact (with priority products defined by committee, and always out of date) proliferating (as mainstream products deliver access too, increasingly), declining in relevance (due to technology development), and over-focused on products rather than the services that are around them. It is also devoid of a connection to a broad, operational DJ framework, that would attach the AT to its 'Why?'. Additionally, the ownership of the definition by WHO is challenging because of its medical association, which puts some in the disability movement off from engaging with AT.

To begin to address this, I proposed an evolution of the AT definition to make it more relevant in the current context for the poorest disabled people in Chapter 6. In considering the evidence presented in Chapters 7 and 8, I now make two further additions, in italics/ bold, based on the data showing that recognition and DJ are strongly connected to the 'Why?' of AT.

> *"Assistive Technology (AT) is an umbrella term covering the devices, systems and services related to the delivery of assistive products which maintain or improve an individual's* ***choice to do the things they value and be recognised for who they truly are****. AT is a strategic prerequisite to pursuit of human well-being and collective and creative justice practices, for those who need it. Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids are all examples of traditional assistive products; and increasingly mobile devices, digital solutions, and mainstream human-computer interaction also function as AT*. ***AT is a necessary demand of disability justice."***

Figure 23: Final proposed new definition of AT (first published in Austin and Holloway, 2022)

The definition connects AT to its 'Why?' and recognises the critical importance of AT in enabling human flourishing. I proposed this definition in a recently published paper (Austin and Holloway, 2022) in a special edition on AT and Sen's Capability Approach. I loosely borrowed Sen's idea of 'Equality of What?' (Sen, 1980), in which he questioned the idea of the basis for understanding justice and wellbeing in his seminal Tanner lecture and asked, 'AT for what?', building on the themes in the studies in this thesis. In order to answer the question of 'AT for what?' I will now move on to the definition of DJ that emerged from the data in Chapter 6.

9.4 RQ2: Defining Disability Justice

Chapter 6 looked at the claims for justice and the definition of justice. I used the same research methods and considered the data using the Participatory Disability Justice Framework I set out in Chapter 3.

I found that there was no common understanding of DJ globally, nationally or locally, and that the only commonality in approach was a broad appreciation of the CRPD. While hard won and helpful in some ways, this type of global treaty is not an operational framework that can drive programmatic interventions or deliver recourse to justice for poor people at a local level. Thus, I sought to test and build out the framework to see if it fits as a good definition given the data.

In terms of **representation**, Chapter 7 revealed that the structure of formal participation for disabled people living in conditions of informality was largely limited to voting, and this felt important though limited. However, within the informal structures of the settlements representation could also mean, for instance, attending community meetings, joining savings groups, or supporting the cleaning or development efforts. All of these activities were also valued by participants, but while in the mainstream settlements disabled people did not participate in them, in HEPPO they led them. I formed the following definition of the representation element of DJ as follows:

Disability Justice: Representation - disabled people participate and lead

Disabled People and able to identify, speak about, collectivise around, influence, lead and nominate other to lead, policy and practice on issues which are valued; at each constituent level (local, national, international); both formally and informally. The voices of disabled people from all backgrounds are understood and valued - alongside others - and leaders who are (poor) disabled people themselves are seen and heard as commonplace. Political processes are democratic inclusive, accessible, and pluralistic.

To delve a little deeper, there is also a story to tell, beyond representation, which encompasses how justice is aligned to **recognition**; 'feeling heard and being seen' was an important aspect of the things disabled people valued. When participants in the mainstream settlements (Dworzark and Thompson Bay) began to meet together for the AT2030 project, they evidentially found value in their collective engagement. No instances of meeting together or talking about disability in the settlement were remembered by participants before 2019. Prior to 2019 disabled people in the mainstream settlement did not know each other at all and disability was recognised positively for the first time that year. This leads me to validate and re-enforce the idea that recognition as an element of DJ was evidenced as relevant in the data. In Chapter 7 I defined the recognition element of DJ as follows:

Disability Justice Recognition - *disability identity is recognised positively*

… in all of its diversity; avoiding misrecognition due to the stigmatisation of disability identity, invisibility and reification of disability identity detached from other concerns about justice, in society.

Redistribution too, was important both in terms of access to immediate livelihoods (including the behaviour of begging as well as access to employment and enterprise) and in order to enable collective action toward redressing the conditions which keep people in (urban) poverty. The evidence suggested that AT was vital to reach for more resources now, and to seek to transform the mechanism allocating the resources later.

In Chapter 7 I defined the redistribution element of DJ as follows:

Disability poverty is tackled

…within an overarching strategy for redistribution of wealth and wellbeing (from the few to the many). Overturning maldistribution is not hindered by implicit or explicit normative framing around productivisim, or displaced by identity politics

Finally in terms of **Disability Relations**, disabled people in the HEPPO settlement were perhaps more direct and articulate about the role of leadership by disabled people in making claims for both AT and DJ; they made calls for their own expertise in their own struggles directly and repeatedly. HEPPO's connection to the DPO sector was as stark as its people detachment from organisations of the urban poor despite their site being less than a ten-minute walk (admittedly much longer using a wheelchair up a huge hill) from the FEDURP headquarters, in Dworzark. This disconnect is significant and was a theme that appeared in the international data too. The lack of connection between the disabled people's organisation working for some version of DJ, and those working for and with urban poor people was shown at every level.

It seems that these connections have been fractured due to a combination of scarcity of resources, the nature of discrimination and the assumptions and practices that have evolved in need for survival. I want to emphasise that this disconnect appeared to be present in both directions. I do not criticise either party who are doing their very best for their constituent group in very tough circumstances. However, a bridge is needed, and the conditions of each landing site must be understood in order to construct it. In Chapter 7 I defined disability relations as:

> ***No body/mind is left behind** in a broad-based movement for justice;*
>
> *both the intersectionality between disabled people and the relations between disabled people and wider social movements are recognised and supported. Disabling relations are overcome. Disability justice is a core part of a broader economic and social justice movement.*

In summary, these elements of the Participatory Disability Justice Framework I constructed in Chapter 3 from Fraser's and Sins Invalid' own approaches, seemed to fit the data well. The evidence I gathered assimilated into the four elements, and I was able to build out their definition from the data. I do not wish to pretend these definitions are anything but a rudimentary initial starting point for further thinking, but in terms of a participatory approach to justice adapted for disability, the framework I define, I suggest, is a starting point for the further research needed with poor disabled people leading the charge. I used this understanding of justice to then examine the relationship between the AT and DJ, to answer the third research question.

9.5 RQ3: The relationship between AT and DJ

In Chapter 8, with the same methods as before, I examined each element of the justice framework against the evidence to identify its relationship with AT access. AT access was found to be both necessary for participation but also a desired result of it. However, being excluded from claims-making was challenging for many, and there was evidence that the lack of AT access led to a lack of collective participation or advocacy on disability issues. AT functioned as *recognition* too, which I did not expect, enabling participants to feel their needs and thus themselves were valid (not 'in-valid'), even if those needs were not met. Participation on a collective level was valued, and of course enabled or not enabled by AT.

The immediate need for survival was evidentially either facilitated by AT access, or not. Not everyone did survive though it is impossible to correlate this sad outcome with a lack of AT directly.

Further, though, the ability to participate in action which might bring into force a new way of organising resources, through collective action, also required AT. Disabled slum dwellers wanted to participate in activities that might drive practical and transformational change, but their participation was directly dependant and often limited by the lack of AT, as well as other factors such as stigma.

I therefore found that AT is a necessary factor in enabling Participatory Disability Justice (according to my definition) and I characterised the four areas of enablement as follows:

*AT enables the **representation** of disabled slum dwellers in the political processes, debates and struggles they wish to prioritise, both formal and informal. AT supports the avoidance of misrepresentation.*

*AT enables positive **recognition** of disability identity for individuals and collectively in the context of intersectional humanity. AT supports the avoidance of invisibility and misrecognition.*

*AT enables **redistribution** both in terms of access to ‘wealth/ assets’ and claims-making toward such. AT supports the avoidance of maldistribution.*

*AT enables positive **disability relations** through facilitating radical inclusion; cross movement solidarity and – to a lesser extent - by helping to ensure intersectional participation. AT is part of the means of avoiding disabling relations*

I conclude that when we view justice as Participatory Disability Justice, which the data suggests we might, AT access significantly mediates recourse in all elements. This applies to the formal and informal, political and practical, individual and collective contexts. This leads me to understand AT as a necessary factor in justice, but not sufficient alone to secure it. Moreover, AT also appears to mediate recourse to personal validation and external recognition, simply through offering the chance of being seen and feeling heard, even when that AT is not provided.

I now want to move on to explore three thematic salient issues in more detail in turn.

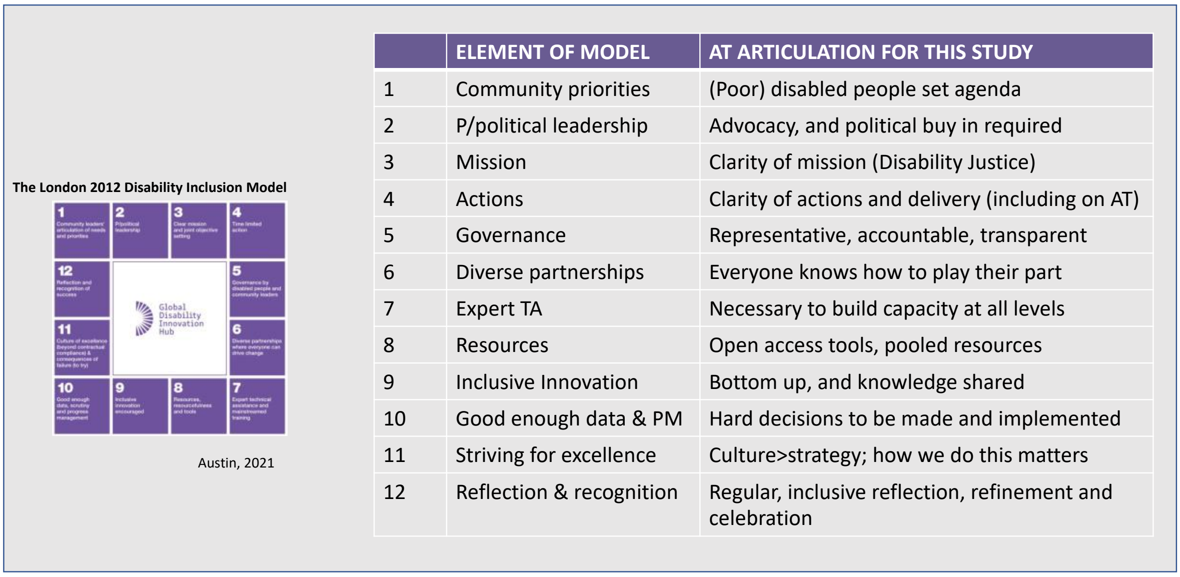
9.6 AT as the *mechanism* and DJ as the *mission*

If a new definition of AT, similar to the one proposed, was adopted globally, it would be a recognition that AT is the *mechanism*, and DJ is the *mission*.

From my participation in various high level global discussions over the past five years, as well as this research, I know that this mission approach for AT is broadly supported in words but not so much in action. Yet the data in this study reveals it to be both vital and pressing to adopt a common operational framework or mission.

While considerable evidence exists that a mission-led approach could be necessary for AT access to be transformed, the literature review revealed divided views on how that mission should be anchored, as our recent working paper on a mission-led approach to AT showed (Alba et al., 2021).

Further, missions need plans and process to succeed. Our recent paper on the 2012 Disability Inclusion Model set out the core 12-steps that enabled success for the integration of DJ for the 2012 Paralympic Games (Austin et al., 2021b), as shown in Chapter 2. I return to this now to map the London 2012 framework to an articulation of AT, if we are to consider the needs of the poorest disabled people. This was first published in a recent paper.(Austin and Holloway, 2022).


The London 2012 Disability Inclusion Model

Austin, 2021

	ELEMENT OF MODEL	AT ARTICULATION FOR THIS STUDY
1	Community priorities	(Poor) disabled people set agenda
2	P/political leadership	Advocacy, and political buy in required
3	Mission	Clarity of mission (Disability Justice)
4	Actions	Clarity of actions and delivery (including on AT)
5	Governance	Representative, accountable, transparent
6	Diverse partnerships	Everyone knows how to play their part
7	Expert TA	Necessary to build capacity at all levels
8	Resources	Open access tools, pooled resources
9	Inclusive Innovation	Bottom up, and knowledge shared
10	Good enough data & PM	Hard decisions to be made and implemented
11	Striving for excellence	Culture>strategy; how we do this matters
12	Reflection & recognition	Regular, inclusive reflection, refinement and celebration

Figure 24: Disability Inclusion Model applied to AT, reproduced from Austin and Holloway (2022)

As shown above, the specific aspects of AT that would require attention, given their current status to meet the approach set out in London 2012 includes prioritisation of:

- better enabling of the views of poor disabled people (and their representatives) to become priority-setting contributions and ensure their continued engagement in governance and partnerships;
- clarification of the global mission (DJ/ AT) and objectives (AT) so that everyone anywhere knows how to play their part in contributing to this mission;
- opening up access to data, tools and resources that can be widely used; and
- strengthening the partnerships between actors linked to the clarified mission.

All of this begins to offer some shape to the principles that might be the basis of an operational framework for AT access, framed in DJ. What type of justice we seek will change if we aim to reach the poorest disabled people. This is not only the case for disability.

In ‘Feminism for the 99%: A Manifesto’ (Arruzza et al., 2019), Arruzza et al. presented two types of justice for feminists, *‘lean in’* style *corporate feminism* or, *feminism for the majority*. Taking this thematic is useful, because the type of AT interventions being led and delivered, especially with the Global North actors leading most of them, could also be categorised as addressing either ‘corporate disability equality’ or ‘majority-world DJ’. This helps to clarify the discussion about what type of justice will be helpful to aid the poorest disabled people.

Below I set out an extrapolation of Fraser’s analysis for the context of disability and AT.

	Understanding of disability justice	**Core actors**	**Role of poor disabled people?**	**AT viewed as…**	**Measures of success**
Corporate Disability Equality	• Equality for disabled people to live in an equal (similar) way to non-disabled people in their existing context • Addresses recognition, but not redistribution or necessarily representation	• Corporate sector • Media • Governments • Institutions and Donors • DPOs	• Not core actors – representation of this group not essential • could be ignored by interventions	• A means to engage in economically productive activity (e.g., work or education)	• Numbers of disabled people participating (for e.g. in education and employment) similar to non-disabled people
Disability Justice for the 99%	• Disability justice as a core aspect of justice for all people and the planet. • Disability justice addresses recognition, representation and redistribution	• Activists • Political leaders • Community Orgs • Environmental and Gender leaders • Mainstream justice campaigns • DPOs	• Poor disabled people are core actors in the struggle for justice for all	• A human right and a necessary for participation in all aspects of life • A transitional demand of a new paradigm	• Fair representation of 99% - including disabled people – among political leadership • Economic, social and pollical prioritisation of the needs of the poorest people

Figure 25 Models of Disability Justice

What the table shows, is that only DJ for the 99% values disabled people as key actors in the struggle for justice and only this version of justice fits this evidence of AT as more than mechanism to be more productive. Only DJ for the 99% approach, seems to fit the data I have gathered in this thesis.

Yet, in lieu of any commonly adopted DJ framing, or public discussion about what it means to engage the poorest disabled people, the policies and reports produced, from ATscale, the WHO and/ or the government of SL, all work on the basis of assumption that AT support of economic production is the smallest part of the story, that . AT works for economic empowerment. This is in fact a valued aim of disabled slum dwellers - livelihoods are for sure desirable and AT is seen as a step toward them – but this should not be the sole aim of the 'for what?' of AT unless we intend to reproduce the structure of the neo-liberal status quo, and adopt a model of justice which denies transformational change. In short, this approach does not deliver DJ for the 99%.

Furthermore, the chasm between the CRPD and the AT interventions is too great to avoid partner programmes drifting off course, perhaps addressing mainly corporate equality, rather than DJ for the majority of disabled people in the world. To return to my results, I proposed adopting Participatory Disability Justice, or some evolved version of it further tested, as 'DJ for the 99%', and therefore to view AT as a necessary factor in the achievement of that justice.

However, I am going to go one step further, and make the case that AT is actually a transitional demand of DJ.

9.1AT as a transitional demand of justice

Though the Social Model of Disability is built of the materialist tradition, its focus on social rather than medical, or bio/ psycho relations of impairment has rendered it rather quiet on AT, which is viewed by some in the disability rights movement as too medical to focus on (as we have seen). What the social model does, is to centre participation i.e., *"nothing about us without us"* in common with the principles of Sen's/ Nussbaum's Capability Approach. Findings from this study also confirm that participation is valued by urban poor people, and AT is necessary to achieve it. Furthermore, there appears to be some considerable shift in or gain, or transformation attained by those who are able to participate and participate collectively.

Perhaps this might be described as consciousness-raising by Marx (Marx and Engels, 1948) or participation may be valorised as a means as well as the end game of development according to (Sen, 1999); it is certainly a core element of Justice as Parity of Participation by Fraser (Fraser, 2005). In this context, AT becomes much more than a tool to aid functioning, as WHO suggests, but rather it functions to enable the necessary participation in deciding what to transition towards in (disability) justice terms.

In Chapter 2, I refer to Trotsky's traditional definition of Transitional Demands (Trotsky, 1938, p. 88) which are presented as a bridge between what it achievable today (the minimum programme) and what is needed for a better future (the maximum programme). In the context of the exploration I have undertaken, I believe the evidence points to AT as both a necessary element of the *minimum programme* as related to the current paradigm and consciousness within neo-liberal late capitalism (for instance AT is needed for school or education) and its access is also a goal in itself.

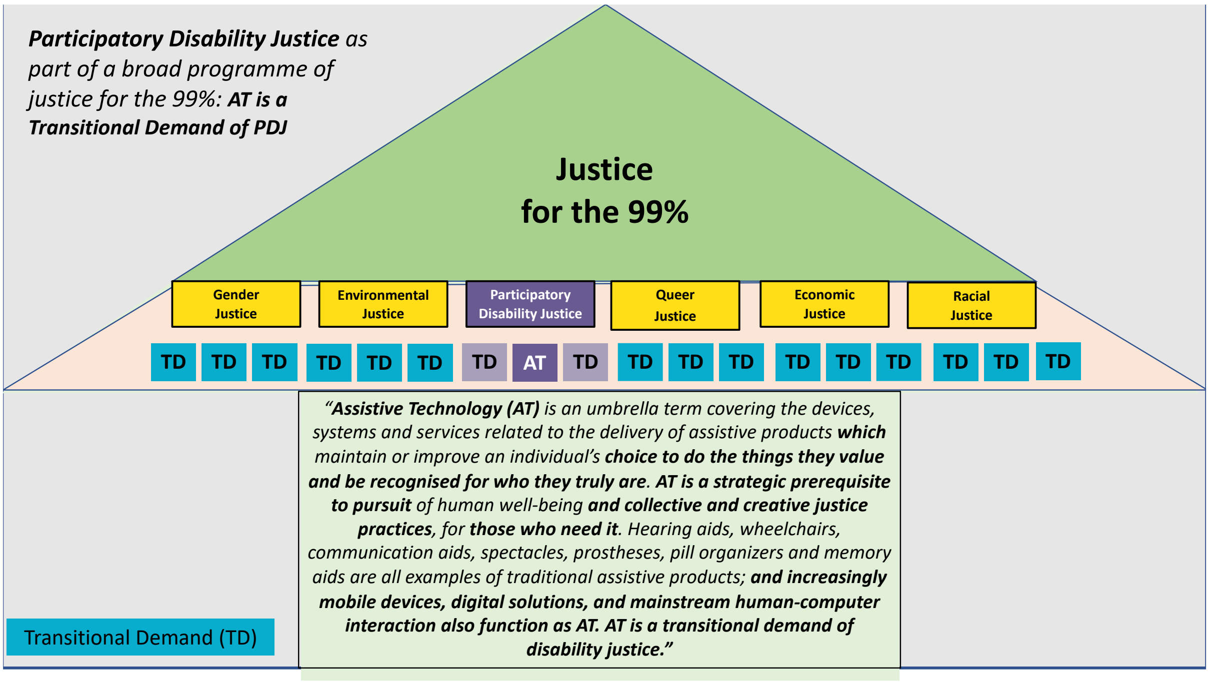
However, AT is also a bridge to the *maximum programme* which is seeking a better future for all (except the 1% perhaps) given the struggle towards a society that removes the conditions of poverty and discrimination experienced by the participants in this study and many others. In Chapter 2 I made the comparison with Faser's idea of affirmative and transformative solutions (2005), and this brings us right back to her ideas about justice for the majority in today's context. AT is needed to both enable inclusion in society as it is and enable participation in the claims for a reorganised transformed society.

Thus, I claim the evidence points to the fact that AT is a transitional demand of DJ. Therefore, we must recognise that AT plays a significant and strategic role in the transition to a different paradigm, as well as acting as an enabler of life within this one. For urban poor people it is even more necessary given the precarity of everyday life is so much greater.

I term AT as a transitional demand of DJ and adjust my definition to reflect this (Figure 24). However, in common with other transitional demands, AT is not sufficient alone. It is not a silver bullet, and it must be linked to a broader framework for justice for disabled people within a fight for justice for all people. This is the final point I will now turn to.

9.2 Participatory Disability Justice as part of the struggle for Justice for all

In recent work, Fraser called her version of 'Justice for the 99%' a 'Trans-environmental Ecosocialism' and highlighted the need for a broad platform for action (Fraser, 2019). Through proposed transitional strategies Fraser considered that a broad coalition for a better future could work collaboratively to achieve seismic interim wins, which were able to both improve the status quo and build support toward the future with these transitional demands in place. I suggest, based on the considerable evidence presented here, that AT interventions should be placed within a Disability Justice Framework which is anchored into a common mission of justice for the 99%, if, in fact, we wish to be certain that AT interventions are to benefit the poorest disabled people. The diagram below presents this idea diagrammatically along with the final refreshed definition.



*“**Assistive Technology (AT)** is an umbrella term covering the devices, systems and services related to the delivery of assistive products **which** maintain or improve an individual’s **choice to do the things they value and be recognised for who they truly are. AT is a strategic prerequisite to pursuit** of human well-being **and collective and creative justice practices**, for **those who need it**. Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids are all examples of traditional assistive products; **and increasingly mobile devices, digital solutions, and mainstream human-computer interaction also function as AT. AT is a transitional demand of disability justice.”***

Figure 26:AT as a Transitional Demand of Participatory Disability Justice

Why is it important to situate DJ within a framework of justice for all? I want to diverge one last time, to consider the nature of this disconnect between organisations of the urban poor and disability organisations. Firstly, I look at the disconnect in Freetown. As a community-based organisation of the urban poor, FEDURP is staffed by volunteer slum dwellers, creatively trying to build up community consciousness to make change. Slogans like: ‘*we are poor but not powerless’* and/ or ‘*information is power’* are literally chanted at meetings and written on the wall. This idea of raising collective agency, building up collective hope and expectation of better relates to Appadurai’s ‘Capacity to Aspire’ (Arjun Appadurai, 2004). This is precisely what SDI’s affiliates built their model upon, and FEDURP is no different. The collect saving, community meetings, and data collection from their own people are what they use to make incremental changes and lobby. They take action towards their own futures every day. They build hope. This is vital and psychosocially important.

Now, let’s add to this the fact that disabled people are often hidden and never meet collectively in the mainstream settlements, and have highly stigmatised identities. The only encounter with visible disability non-disabled settlement dwellers might have happens through the street beggars. This image of disability - literally holing out the hands of desperation for money/ help from another - flies in the face of the SDI model. It appears to revoke all notions of agency and leadership by the community members in their own struggles. It appears weak, individualist, un-aspirational. Yet, conversely – in AT terms at least – people in the HEPPO community (who largely survive on street begging) have their AT and are anything but weak, individual and lacking in agency. HEPPO members have strong advocacy links and are able to use the Human Rights legislation to fight eviction. Thus, what appears weak and hopeless, and a symbol of disabled people being ‘other’ to the collective actions of the urban poor community is actually an illusion.

Similarly, because FEDURP members are working so hard to save such a tiny amount to build the most basic facilities (like toilets) in the community (in lieu of any government support), they have in the past neglected to build these in accessible forms. It looks (from the outside) as though they do not validate disability inclusion. Quite the opposite is true I found, and through the study the opinion of FEDURP's leaders changed; disability identity was positively recognised. An emphatic apology was even given for the inaccessible toilets. This is just an example, but the bridge between CBOs and DPOs remains unbuilt. Albeit some signs of collaboration were emerging in the latter parts of this study, particularly between CODHOSAPA and SLUDI. It can be further incentivised through the design of programmes and funding.

Internationally too, this connection is fractured. The interviews revealed that while the forward-thinking leaders of global disability organisation are now well engaged with the AT agenda, there is still a disconnect, as some feel AT is too medical and there is an effort to 'fix' the problem. Mostly these global leaders did not experience (did/ do not live in or come from) poverty. Additionally, in my experience, for mainstream activists and practitioners of development feel there are so many people who need support and so many issues to tackle, that disability can be tackled next. Let's be clear, this leads to disability issues not being tackled at all.

My evidence and experience suggest that the (relatively) poorly resourced International Disability Alliance is a stalwart but can only do so much. Without a UN unit similar to UN women, a lot falls to them, including the organisation of the bi-annual Global Disability conferences, and sitting on the thematic boards of almost everything of significance including ATscale. This is solvable, but not without a proper framework that links interventions on AT to DJ claims, to broader justice claims. This is most vital for those struggling in both contexts, the poor disabled people themselves.

9.3 Limitations of the study

The study was initiated in 2018 with the first formal field trip carried out in 2019, prior to the COVID-19 pandemic. The pandemic caused Sierra Leone to declare a state of emergency in March 2019, and the university to restrict all travel for 18 months. This resulted in the final set of interviews with local participants being conducted online, via local research partners which may have prejudiced the quality and quantity of the latter data from slum dwellers themselves. This has been mitigated through cross-referencing with other data sources (to ensure quality of results) and adding an international data set – interviews with global AT, and DJ experts. Although not originally envisaged, this pivot has allowed for the results to be both more revealing and more relevant in global policy terms and ultimately has led to a more strategic study. What was not possible though in this context, which had originally been envisaged, was more detailed investigation in the ways that autonomy of disabled people in the HEPPO site (and potentially others) interacted vis a vis the disabled people living in the mainstream settlements. This is interesting conceptually regarding the work on urban informality, and would warrant a more thorough, anthropological investigation.

Moreover, the data captured for this work cut off in November 2021 for practical reasons. While much of the thinking and the evidence of AT2030 fed into the Global Report on AT, it has not been possible to extend the timeline to encompass the final published report, given it was delayed from May 2021 to Mid-2022 due to COVID-19. It will be interesting to see how the findings of this study sit alongside the World Report data and priorities. Similarly, ATscale, the global partnership on AT, is taking a renewed role leading the global AT agenda, and it will be interesting to see in these coming years how the AT agenda develops at this pivotal time. Hopes are high for urgent and impactful work which should be usefully critiqued through research.

Similarly, this study presented suggestions for policy implementors, and it would be interesting to gather longitudinal data or evidence, though this was out of scope of this investigation. A core limitation of this work is the ability to test these recommendations in practice then, to understand if they are implementable in context. I have used a relatively small case study, and a particular context, so all findings will need to be tested in other contexts if they are intended to be more widely adopted.

Additionally, it was initially intended that this work would be participatory. It is not claimed as such now. In part due to COVID-19 and the remote working practices in place, also considering the limitation of resources and the needs of PhD study. It was not possible to undertake the kind of genuinely participatory activity in terms of participatory research coding, analysis, and recommendation setting. This is regrettable yet perhaps understandable in the circumstances. Every effort was made to ensure disabled people's voices 'speak' through the data wherever possible. A next stage of activity would be to test this thinking in practice with people most affected.

Holding these limitations in mind, this work is presented with integrity as robust and sound evidence in service of its intention, improving the lives of the poorest disabled people.

9.4 Recommendations

9.4.1 Further research

What arose here, was something very interesting in relation to the power of AT to unlock human hearts on an individual and a collective level. I have articulated this where the evidence allowed, including through the proposed new definition of AT. However, it goes further than the scope has allowed and really an anthropological investigation would be warranted as this touches profoundly on psychology as well as social development. It would seem that what I have termed creative justice practices are allowed for when individuals feel seen and valued, and AT has a clear and key role in that unlocking, from community participation, to friendships, and to collective demands, these practices tend to be outside of what might usually be considered (work, education etc) as a positive outcome form AT use. Still, they appear strategically connected to empowerment, awakening and participation in struggles towards justice. It would be very interesting to explore this further.

Further research might consider:

- whether the findings hold in other contexts;
- if the definition of Participatory Disability Justice can prove operationally useful;
- issues of intersectionality especially whether the issues present differently for older persons, who may not describe themselves as disabled;

- what happens to this group if they are given AT; and
- how the success of HEPPO in getting 71% AT access can be replicated by others.

9.4.2 Extrapolation of the findings for AT Policy making

Much of the thinking about justice is abstract, and to some degree the conclusions in this study are so too. However, it feels important to relate those as much as possible to the realities of today's situation. To that end the pragmatic next steps proposed below are in relationship with the data and the theoretical findings of the study.

Internationally, actors could:

- address AT access in mainstream Donor funded programmes (not just targeted disability programmes);
- explicitly connect AT to an operational framework for DJ with a common mission for all actors; Implement a London 2012-style framework of delivery;
- find ways to connect the poverty, AT and DJ agenda's actions and actors to a core framework for intervention with recourse to accountability to those most affected;
- improve coordination and donor support to meet local priorities set locally, as well as international priorities;
- support the national governments to lead interventions in their own countries, working with communities most affected; and
- elevate the voices of the most affected communities to agenda-setting level.

Nationally, actors could:

- address implementation of Disability Act & commitments made under CRPD;
- keep and deliver the new priorities on AT provision, with global support;
- address independence and representation on the National Commission, especially by urban poor disabled people;
- develop opportunities for connections and mutual support between organisation of the urban poor and disabled people's organisations;
- offer funding for community-based organisations to continue to develop disability inclusive approaches including representation of DP in activities and leadership; and
- support funding for organisations of disabled people working locally to engage with urban poverty groups and campaigns including representation of urban poor people in activities and leadership.

Locally, actors could:

- share learning and practice through federations nationally and globally; and
- work together towards justice for all, continuing to push and challenge themselves on inclusion.

10 Conclusion

This study set out to understand the role of AT in mediating recourse to DJ with a focus on urban poor people using a case study in Freetown, Sierra Leone. The research was conducted between 2018 and 2021 and drew on six data sets incorporating qualitative primary research with disabled slum dwellers, stakeholders and international experts, alongside a review of the wider AT2030 study data and relevant policies.

In summary, this study found that **AT is vitally needed and critically lacking for most** disabled people at every level – local, national, and international. Yet, locally, the **autonomously organised group of disabled slum dwellers had phenomenally better access** (71%) to AT than those who lived in mainstream settlements and were not collectively organised (15%).

Further, momentum to address AT access has current traction at all levels, but **the definition of AT commonly used at present is losing its validity**, leading to the potential for mission-creep and perverse incentives. With limited resources, and new actors entering the field, it is vital to urgently mitigate this by providing needed clarity. It is important to understand the 'for what?' of AT (Austin and Holloway, 22) to know what success looks like.

AT should therefore be better framed within a commonly understood, operationally-sound, accountable framework for DJ. The study has explored and found helpful, a framework for DJ composed of 4 elements: **representation, recognition, redistribution and disability relations,** offering initial definitions for each elements on which these are build. I have called this framework *Participatory Disability Justice* to reflect its origins and the centrality of participation.

This framing of DJ must also **connect to the broader claims for justice** of poor people and people in general, be it economic, social and/ or cultural, given the evidence in this study shows that DJ claims are often side-lined behind the day-to-day claims for survival of those living in conditions of precarity.

To be effective, broad justice claims must take good account of disability inclusion, as they likely must also be intersectionally relevant to other terms (faith, race, gender), and must connect to wider struggles against the oppressive aspects of neo-liberalism (for environmental justice for instance).

AT enables DJ. However, it is more than a simple element, interchangeable with other elements. Rather it should be viewed as **a transitional demand of justice because of the critical role of AT in enabling participation** of poor disabled people; in their own struggles for emancipation and in shaping the claims they wish to make. Also significant is the role of AT in enabling the recognition of people as valid and valued.

This study also reveals that the day-to-day consequences of juggling struggles for water, shelter, food and sanitation with the implications of disability as a pejorative identity often render **DJ and AT claims to background conditions for disabled slum dwellers living in mainstream settlements**.

These are vital and pressing concerns; in the wider AT2030 study group I was told that eight of the disabled settlement dwellers lost their lives during the study from causes related to poverty, lack of access to AT or the essential medicines necessary to manage their conditions. Another participant talked of ending their own life if they could not access AT. Let us not be under any misapprehension that while global leaders debate, poor disabled people in countries like SL die from lack of access to AT; this issue is vital and pressing.

In addition to being necessary for access to livelihoods or education, the evidence suggests that missing AT prevents participation in vital strategic action and claims-making, which is necessary to bring about a better future. The critical lack of AT access also had acute consequences for the participation of poor disabled people in their own community structures of (informal) governance. This had even more relevance because community structures were often the only recourse to participation in collective action for a better future that existed at all, due to the absence of state provision or presence in the settlements. I posit therefore, that in conditions of precarity AT access is even more vital.

The study indicated that through participating collectively alongside other disabled people, disabled slum dwellers living in mainstream settlements grew in confidence, and the community-based organisation that work in the settlements also gained knowledge and offered commitment to tacking issues of disability exclusion. The data suggests that even talking collectively about AT can help to offer recognition and can turn expectations of exclusion into expectations of inclusion.

Conversely, those disabled slum dwellers who lived in autonomous settlement together, still experienced the harsh effects of poverty. Yet, largely they were able to access AT, to engage as a DPO with their rights under the CRPD to some degree, as well as attract political attention. This is a small case study, conducted under particular conditions, but compared to the stigma and exclusion on the grounds of disability experienced in the mainstream settlement this difference makes a stark case for more exploration of the role of autonomous participation in this context.

AT is not a silver bullet. Ableism in society, as well as in the production, distribution and allocation of AT, can also reinforce power dynamics and exclusion. The assumption that AT is a way to ‘fix’ disabled people and ‘normalise’ bodies that are different is a risk which must be mitigated through engaging AT users in decision making and even the production of AT. **AT is as much a product of the type of society it emanates from as anything else,** and at present that is neo-liberal capitalism. Therefore, perhaps the most significant of the issues found here is the lack of connection between AT and a clear operational framework for justice. The disconnect between disabled people’s organisations and organisations of the urban poor is also problematic and was evidenced at every level. Connections have been fractured due to the nature of discrimination, and the assumptions and practices that have evolved for survival. However, another future is perhaps possible and many actors were keen to bridge this gap. I present a framework for Participatory Disability Justice in order to begin further work to examine how we might do this in future; for the 99%.

I end where I began, borrowing a style and taking significant licence to adapt from Appadurai (Arjun Appadurai, 2004), as I did in the introduction:

> ***Disability Justice is many things, all of them good. It is equal representation and fair distribution of resources, balancing the health of the planet and the quality of life of its inhabitants. It is security, recognition, and dignity for all. It is collectively managed risk and support; and shared comfort. It is radical, intersectional***

> ***inclusion materialised. For every mind and every body, it enables human flourishing.***

I hope that the notion of DJ I have explored in this thesis, provides a contribution towards much-needed further thinking and action.

This study concludes that AT is a *mechanism*, while DJ is the *mission*. That mission, like all, must be led by those who experience the harshest effects of inaction, for in their wisdom lies the answers. Without AT access, this type of participation simply will not be possible.

References

Abbott, C., 2007. Defining assistive technologies - a discussion. J. Assist. Technol. 1, 6–9. https://doi.org/10.1108/17549450200700002

Alba, sarah, Austin, Victoria, Holloway, Catherine, Kattal, Rainer, 2021. New economics of assistive technology: A call for a missions approach. UCL Institute for Innovation and Public Purpose Working Paper Series.

Albala, S., Austin, V., Holloway, C., Kattel, R., 2021. New economics of assistive technology: A call for a missions approach. UCL Inst. Innov. Public Purp.

Ambos, B., Brandl, K., Perri, A., Scalera, V.G., Van Assche, A., 2021. The nature of innovation in global value chains. J. World Bus. 56, 101221. https://doi.org/10.1016/j.jwb.2021.101221

Appadurai, Arjan, 2004. The Capacity to Aspire: Culture and the Terms of Recognition, in: Rao, V., Walton, M. (Eds.), Culture and Public Action: A Cross-Disciplinary Dialogue on Development Policy. Stanford University Press, Palo Alto, California, pp. 59–84.

Appadurai, Arjun, 2004. The Capacity to Aspire: Culture and the Terms of Recognition. Cult. Public Action 59–84.

Appadurai, A., 2001. Deep democracy: urban governmentality and the horizon of politics. Environ. Urban. 13, 23–43. https://doi.org/10.1177/095624780101300203

Appadurai, A., Abélès, M., Belier, I., Jelin, E., 2001. Democracy from Below 13, 23–44.

Arruzza, C., Bhattacharya, T., Fraser, N., 2019. Feminism for the 99%: A Manifesto. Verso Books.

ATscale, 2020. The Case for Investing in Assistive Technology. [WWW Document]. https://atscalepartnership.org/investment-case accessed 6.24.21).

ATscale, 2019. Strategy Overview. [WWW Document] https://atscalepartnership.org/investment-case (accessed 6.24.21).

Austin, V., 2021. Popular culture can set stigma alight in seconds but to sustain change the fire must be ready to burn. Glob. Disabil. Innov. Hub. URL https://www.disabilityinnovation.com/blog/paralympic-legacy (accessed 7.4.21).

Austin, V., Holloway, C., 2022. Assistive Technology (AT), for What? Societies 12, 169. https://doi.org/10.3390/soc12060169

Austin, V., Holloway, C., 2019. Overcoming systematic global barriers to AT: a new methodology and quickstart testing through a£ 20m programme.

Austin, V., Holloway, C., Ossul Vermehren, I., Dumbuya, A., Barbareschi, G., Walker, J., 2021a. “Give Us the Chance to Be Part of You, We Want Our Voices to Be Heard”: Assistive Technology as a Mediator of Participation in (Formal and Informal) Citizenship Activities for Persons with Disabilities Who Are Slum Dwellers in Freetown, Sierra Leone. Int. J. Environ. Res. Public. Health 18, 5547. https://doi.org/10.3390/ijerph18115547

Austin, V., Mattick, K., Holloway, C., 2021b. "This Is the Story of Community Leadership with Political Backing. (PM1)" Critical Junctures in Paralympic Legacy: Framing the London 2012 Disability Inclusion Model for New Global Challenges. Sustainability 13, 9253. https://doi.org/10.3390/su13169253

Banks, L.M., Kuper, H., Polack, S., 2017. Poverty and disability in low- and middle-income countries: A systematic review. PLOS ONE 12, e0189996. https://doi.org/10.1371/journal.pone.0189996

Barbareschi, G., Holloway, C., 2020. Understanding independent wheelchair transfers. Perspectives from stakeholders. Disabil. Rehabil. Assist. Technol. 15, 545–552.

Barbareschi, G., Holloway, C., Arnold, K., Magomere, G., Wetende, W.A., Ngare, G., Olenja, J., 2020a. The social network: How people with visual impairment use mobile phones in kibera, kenya, in: Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. pp. 1–15.

Barbareschi, G., Sibylle Daymond, Jake Honeywill, Dominic Noble, Nancy N Mbugua, Ian Harris, Victoria Austin, Catherine Holloway, 2020b. Value beyond function: analyzing the perception of wheelchair innovations in Kenya, in: Proceedings of the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20). Presented at the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20), Association for Computing Machinery, New York, NY, USA.

Barton, S.J., 2021. Access and Disability Justice in Theological Education. J. Disabil. Relig. 25, 279–295. https://doi.org/10.1080/23312521.2021.1895025

Baumann, H., Yacobi, H., 2022. Introduction: Infrastructural stigma and urban vulnerability. Urban Stud. 59, 475–489. https://doi.org/10.1177/00420980211055655

Baylies, C., 2002. Disability and the Notion of Human Development: Questions of rights and capabilities. Disabil. Soc. 17, 725–739. https://doi.org/10.1080/0968759022000039037

Bengtsson, S., 2017. Out of the frame: disability and the body in the writings of Karl Marx. Scand. J. Disabil. Res. 19, 151–160. https://doi.org/10.1080/15017419.2016.1263972

Bengtsson, S., 2016. The two-sided coin – disability, normalcy and social categorization in the New Testament. Scand. J. Disabil. Res. 18, 269–279. https://doi.org/10.1080/15017419.2015.1064027

Berghs, M., 2012. War and Embodied Memory: Becoming Disabled in Sierra Leone.

Berne, P., Morales, A.L., Langstaff, D., Invalid, S., 2018. Ten Principles of Disability Justice. WSQ Womens Stud. Q. 46, 227–230. https://doi.org/10.1353/wsq.2018.0003

Bernts, T., d'Anjou, L., Houtman, D., 1992. Citizenship and social justice. Soc. Justice Res. 5, 195–212. https://doi.org/10.1007/BF01048707

Betancourt, T.S., Simmons, S., Borisova, I., Brewer, S.E., Iweala, U., Soudière, M. de la, 2008. High Hopes, Grim Reality: Reintegration and the Education of Former Child Soldiers in Sierra Leone. Comp. Educ. Rev. 52, 565–587. https://doi.org/10.1086/591298

Bickenbach, J., 2014. Reconciling the capability approach and the ICF. Alter 8, 10–23. https://doi.org/10.1016/j.alter.2013.08.003

Bickenbach, J., 2011. The World Report on Disability. Disabil. Soc. 26, 655–658. https://doi.org/10.1080/09687599.2011.589198

Blaikie, N. (Ed.), 2003. Designing Social Research. BMS Bull. Sociol. Methodol. Bull. Méthodologie Sociol. 82–87.

Blanck, P., 2020. Disability Inclusive Employment and the Accommodation Principle: Emerging Issues in Research, Policy, and Law. J. Occup. Rehabil. 30, 505–510. https://doi.org/10.1007/s10926-020-09940-9

Booth, A., Hannes, K., Harden, A., Noyes, J., Harris, J., Tong, A., 2014. COREQ (Consolidated Criteria for Reporting Qualitative Studies), in: Guidelines for Reporting Health Research: A User's Manual. John Wiley & Sons, Ltd, pp. 214–226. https://doi.org/10.1002/9781118715598.ch21

Borg, J., Lindström, A., Larsson, S., 2009. Assistive technology in developing countries: national and international responsibilities to implement the Convention on the Rights of Persons with Disabilities. The Lancet 374, 1863–1865. https://doi.org/10.1016/S0140-6736(09)61872-9

Braithwaite, J., Mont, D., 2009. Disability and poverty: A survey of World Bank Poverty Assessments and implications. ALTER - Eur. J. Disabil. Res. Rev. Eur. Rech. Sur Handicap 3, 219–232. https://doi.org/10.1016/j.alter.2008.10.002

Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3, 77–101. https://doi.org/10.1191/1478088706qp063oa

Briant, E., Watson, N., Philo, G., 2013. Reporting disability in the age of austerity: the changing face of media representation of disability and disabled people in the United Kingdom and the creation of new 'folk devils.' Disabil. Soc. 28, 874–889.

Brown, B., 2013. The Power of Vulnerability: Teachings on Authenticity, Connection and Courage. Sounds True Inc.

Brown, B., 2006. Shame Resilience Theory: A Grounded Theory Study on Women and Shame. Fam. Soc. 87, 43–52. https://doi.org/10.1606/1044-3894.3483

Bruckner, D.W., 2009. In Defense of Adaptive Preferences. Philos. Stud. Int. J. Philos. Anal. Tradit. 142, 307–324.

Burton, E., Mitchell, L., 2006. Inclusive Urban Design: Streets For Life, 1 edition. ed. Routledge, Amsterdam.

Carew, M.T., Colbourn, T., Cole, E., Ngafuan, R., Groce, N., Kett, M., 2019. Inter- and intra-household perceived relative inequality among disabled and non-disabled people in Liberia. PLoS ONE 14, e0217873. https://doi.org/10.1371/journal.pone.0217873

Castells, M., 2009. The Rise of the Network Society: Wiley-Blackwell.

Chambers, R., 2013. Rural Development: Putting the Last First. Routledge, London. https://doi.org/10.4324/9781315835815

Chambers, R., 1997. Whose Reality Counts? Practical Action Publishing. https://doi.org/10.3362/9781780440453

Chance, K.R., 2012. Living politics: practices and protests of “the poor” in democratic South Africa. J. Pan Afr. Stud. 5, 284.

Charmaz, K., 1996. Constructing Grounded Theory.

Chataika, T., Mckenzie, J., 2016. Global Institutions and Their Engagement with Disability Mainstreaming in the South: Development and (Dis)Connections. https://doi.org/10.1007/978-3-319-42488-0_27

Clotilde, A., 2017. An examination of the Sierra Leone war. Afr. J. Polit. Sci. Int. Relat. 11, 103–111. https://doi.org/10.5897/AJPSIR2017.0994

Corburn, J., Riley, L. (Eds.), 2016. Slum Health: From the Cell to the Street.

Cornwall, A., 2002. Locating Citizen Participation. IDS Bull. 33, i–x. https://doi.org/10.1111/j.1759-5436.2002.tb00016.x

Dabas, H., Deo, S., Sabharwal, M., Pal, A., Salim, S., Nair, L., Chauhan, K., Maheshwari, P., Parulkar, A., Singh, R., Chitalia, M., Kadam, R., Kaur, M., Oghor, C., Ponnudurai, N., Kumta, S., Small, P., Dewan, P., Pai, M., 2019. Initiative for Promoting Affordable and Quality Tuberculosis Tests (IPAQT): a market-shaping intervention in India. BMJ Glob. Health 4, e001539. https://doi.org/10.1136/bmjgh-2019-001539

Danemayer, J., Boggs, D., Delgado Ramos, V., Smith, E., Kular, A., Bhot, W., Ramos, F., Polack, S., Holloway, C., 2022. Estimating need and coverage for five priority assistive products: A systematic review of global population-based research. BMJ Glob. Health.

Danemayer, J., Boggs, D., Polack, S., Smith, E.M., Ramos, V.D., Battistella, L.R., Holloway, C., 2021. Measuring assistive technology supply and demand: A scoping review. Assist. Technol. 33, 35–49. https://doi.org/10.1080/10400435.2021.1957039

David, E.J.R., Derthick, A.O., 2013. What Is Internalized Oppression, and So What?, in: David, E.J.R. (Ed.), Internalized Oppression. Springer Publishing Company, New York, NY. https://doi.org/10.1891/9780826199263.0001

Davis, L.J., 2016. The Disability Studies Reader.

Deepak, S., Kumar, J., Ramasamy, P., Griffo, G., 2014. An emancipatory research on CBR and the barriers faced by persons with disabilities. Disabil. Rehabil. 36, 1502–1507. https://doi.org/10.3109/09638288.2013.800914

Desmond, D., Layton, N., Bentley, J., Boot, F.H., Borg, J., Dhungana, B.M., Gallagher, P., Gitlow, L., Gowran, R.J., Groce, N., Mavrou, K., Mackeogh, T., McDonald, R., Pettersson, C., Scherer, M.J., 2018. Assistive technology and people: a position paper from the first global research, innovation and education on assistive technology (GREAT) summit. Disabil. Rehabil. Assist. Technol. 13, 437–444. https://doi.org/10.1080/17483107.2018.1471169

Dey, I., 1993. Qualitative Data Analysis. A User Friendly Guide for Social Scientist, 1st ed. Routledge.

Dr. Víctor Pineda: A Call for “Radical Inclusion” of Persons with Disabilities, 2015.

Durojaye, E., Mirugi-Mukundi, G., 2020. Exploring the link between poverty and human rights in Africa.

Dutton, W.H., Blumler, J.G., Kramer, K.L., 1987. Continuity and change in conceptions of the wired city, in: Wired Cities: Shaping the Future of Communications. G. K. Hall & Co., USA, pp. 3–26.

Ebuenyi, I.D., Smith, E.M., Holloway, C., Jensen, R., D’Arino, L., MacLachlan, M., 2020. COVID-19 as social disability: the opportunity of social empathy for empowerment. BMJ Glob. Health 5, e003039. https://doi.org/10.1136/bmjgh-2020-003039

Edwards, S., Walsh, S., Blythe, P., Hamilton, N., Soutter, J., 2001. Accessibility in the built and transport environment The wheelchair user perspective. Univers. Access Inf. Soc. 1, 91–98. https://doi.org/10.1007/s102090100013

Farrar, J.J., Piot, P., 2014. The Ebola Emergency — Immediate Action, Ongoing Strategy. N. Engl. J. Med. 371, 1545–1546. https://doi.org/10.1056/NEJMe1411471

FCDO, 2018. Global Disability Summit 2018 - Summary of Commitments.

Florida, R., 2002. Cities and the Creative Class [WWW Document]. URL https://journals.sagepub.com/doi/10.1111/1540-6040.00034 (accessed 7.6.21).

Fraser, N., 2022. Cannibal Capitalism: How our System is Devouring Democracy, Care, and the Planetand What We Can Do About It. Verso Books.

Fraser, N., 2021a. Climates of Capital. New Left Rev. 94–127.

Fraser, N., 2021b. “Cannibal Capitalism” Is on Our Horizon.

Fraser, N., 2019. The Old Is Dying and the New Cannot Be Born: From Progressive Neoliberalism to Trump and Beyond: Amazon.co.uk: Nancy Fraser: 9781788732727: Books [WWW Document]. URL (accessed 6.21.21).

Fraser, N., 2017. 7. Behind Marx’s Hidden Abode: For an Expanded Conception of Capitalism, Critical Theory in Critical Times. Columbia University Press.

Fraser, N., 2014. Behind Marx’s Hidden Abode. New Left Rev. 55–72.

Fraser, N., 2008. Scales of Justice: Reimagining Political Space in a Globalizing World. Columbia University Press.

Fraser, N., 2005. Reframing Justice in a Globalizing World. New Left Rev. 69–88.

Fraser, N., 2000. Rethinking Recognition. New Left Rev., II 107–120.

Fraser, N., 1997. Justice Interruptus: Critical Reflections on the.

Frediani, A., 2007. Amartya Sen, the World Bank, and the Redress of Urban Poverty: A Brazilian Case Study. https://doi.org/10.1080/14649880601101473

Frediani, A.A., 2010. Sen’s Capability Approach as a framework to the practice of development. Dev. Pract. 20, 173–187.

Freetown City Council, 2019. Transform Freetown: an overview 2019-2022. FCC, Freetown, Sierra Leone.

Freire, P., 2000. Pedagogy of the oppressed, 30th anniversary ed. ed. Continuum, New York.

Fukuda-Parr, S., 2003. The Human Development Paradigm: Operationalizing Sen's Ideas on Capabilities. Fem. Econ. 9, 301–317. https://doi.org/10.1080/1354570022000077980

Garland-Thomson, R., 2013. Disability Studies: A Field Emerged. Am. Q. 65, 915–926.

Garthwaite, K., 2011. 'The language of shirkers and scroungers?'Talking about illness, disability and coalition welfare reform. Disabil. Soc. 26, 369–372.

Gaventa, J., 1982. Power and Powerlessness: Quiescence and Rebellion in an Appalachian Valley. University of Illinois Press.

Gaventa, John, 2004. Towards participatory governance: assessing the transformative possibilities, in: Participation: From Tyranny to Transformation? Zed Books.

Ghai, A., Reddy, V.Y., 2020. Assistive Technology Research and Disability Studies in the Global South: the Need for Synergy 6.

Giles, T., King, L., de Lacey, S., 2013. The Timing of the Literature Review in Grounded Theory Research: An Open Mind Versus an Empty Head. Adv. Nurs. Sci. 36, E29. https://doi.org/10.1097/ANS.0b013e3182902035

Glaser, B.G., Strauss, A.L., 1967. The Discovery of Grounded Theory: Strategies for Qualitative Research. Aldine Publishing Company.

Gleeson, B., 1999. Geographies of Disability. Routledge. https://doi.org/10.4324/9780203021217

Glinert, E.P., York, B.W., 1992. Computers and people with disabilities. Commun. ACM 35, 32–35. https://doi.org/10.1145/129875.129876

Goodley, D., 2007. Towards socially just pedagogies: Deleuzoguattarian critical disability studies. Int. J. Incl. Educ. 11, 317–334. https://doi.org/10.1080/13603110701238769

Goodley, D., Hughes, B., Davis, L. (Eds.), 2012. Disability and Social Theory: New Developments and Directions. Palgrave Macmillan UK. https://doi.org/10.1057/9781137023001

Goodley, D., Liddiard, K., Runswick-Cole, K., 2018. Feeling disability: theories of affect and critical disability studies. Disabil. Soc. 33, 197–217. https://doi.org/10.1080/09687599.2017.1402752

Government of Sierra Leone, 2019. Sierra Leone Medium-Term National Development Plan 2019-2023 (National Development Plan). Govt of SL, Freetown, SL.

Graham, S., Marvin, S., 1995. Telecommunications and the City: Electronic Spaces, Urban Places. Routledge, London. https://doi.org/10.4324/9780203430453

Grech, S., 2016. Disability in the Global South - The Critical Handbook. Springer.

Green, D., 2016. How Change Happens. Oxord University Press, Oxford.

Green, D., 2012. From Poverty to Power Praise for this book.

Green, D., 2008. From Poverty to Power: How Active Citizens and Effective States Can Change the World, Pap/Cdr edition. ed. Oxfam Publishing, Oxford : Herndon, VA.

Groce, N., 2019. “Everyone Here Spoke Sign Language.” Begin. Disabil. 68–76. https://doi.org/10.4324/9781315453217-9

Groce, N., Kett, M., 2013. The Disability and Development Gap Working Paper 21 [WWW Document]. URL http://studylib.net/doc/12866950/the-disability-and-development-gap-working-paper-21-1-nor... (accessed 2.14.17).

Groce, N., Loeb, M., Murray, B., 2014. The disabled beggar literature review: begging as an overlooked issue of disability and poverty. ILO Work. Pap., ILO Working Papers.

Groce, N., Trani, J., 2011. Disability and the millennium development goals. U. N. Publ.

Grue, J., 2017. Now you see it, now you don’t: A discourse view of disability and multidisciplinarity. Alter, Sixth Alter Conference, Stockholm, 2016 / Sixième conférence d’Alter, Stockholm, 2016. Guest editors / Coordonné par : Louis Bertrand, Anders Gustavsson 11, 168–178. https://doi.org/10.1016/j.alter.2017.05.002

Grue, J., 2016. The social meaning of disability: a reflection on categorisation, stigma and identity. Sociol. Health Illn. 38, 957–964. https://doi.org/10.1111/1467-9566.12417

GSMA, 2019. Understanding the mobile disability gap. Insights on mobile phone access and usage by persons with disabilities in Kenya and Bangladesh.

Hall, E., Wilton, R., 2017. Towards a relational geography of disability. Prog. Hum. Geogr. 41, 727–744. https://doi.org/10.1177/0309132516659705

Hanebutt, R., Mueller, C., 2021. Disability studies, crip theory, and education. https://doi.org/10.1093/acrefore/9780190264093.013.1392

Hans, A., 2006. Gender, Technology and Disability in the South. Development 49, 123–127. https://doi.org/10.1057/palgrave.development.1100306

Haraway, D., 2013. Simians, Cyborgs, and Women : The Reinvention of Nature. Routledge. https://doi.org/10.4324/9780203873106

Harris, K., Scully, B., 2015. A hidden counter-movement? Precarity, politics, and social protection before and beyond the neoliberal era. Theory Soc. 44, 415–444. https://doi.org/10.1007/s11186-015-9256-5

Harriss-White, B., 2005. Destitution and the Poverty of its Politics—With Special Reference to South Asia. World Dev., Exploring the politics of poverty reduction: how are the poorest represented? 33, 881–891. https://doi.org/10.1016/j.worlddev.2004.09.014

Harvey, D., 2005. The neoliberal state, in: A Brief History of Neoliberalism. Oxford University Press.

Henderson, G., Bryan, W.V., 2011. Psychosocial Aspects of Disability.

Hersh, M., Mouroutsou, S., 2019. Learning technology and disability—Overcoming barriers to inclusion: Evidence from a multicountry study. Br. J. Educ. Technol. 50, 3329–3344.

Holloway, C., 2019. Disability interaction (DIX): A manifesto. ACM Interact. 26, 44–49. https://doi.org/10.1145/3310322

Holloway, C., Austin, V., Barbareschi, G., Ramos, 2018. Scoping research Report on Assistive Technology. On the road for universal assistive technology coverage. Prepared by the GDI Hub & partners for the UK Department for International Development. Global Disability Innvoation Hub.

Holloway, C., Austin, V.,. Barbareschi, G.,. Ramos Barajas, F.,. Pannell, L.,. Morgado Ramirez, D.,. Frost, R.,. McKinnon, I.,. Holmes, C.,. Frazer, R.,. Kett, M. Groce, N.,. Carew, M.,. Abu Alghaib, O.,. Khasnabis, C.,. Tebbutt, E.,. Kobayashi, E.,. Seghers, F., 2018. Scoping Research Report on Assistive Technology; on the road to universal assistive technolgoy coverage.

Holloway, C., Barbareschi, G., 2021. Disability Interactions: Creating Inclusive Innovations. Synth. Lect. Hum.-Centered Inform. 14, i–198. https://doi.org/10.2200/S01141ED1V01Y202111HCI053

Holloway, C., Dawes, H., 2016. Disrupting the world of Disability: The Next Generation of Assistive Technologies and Rehabilitation Practices. Healthc. Technol. Lett. 3, 254–256. https://doi.org/10.1049/htl.2016.0087

Holloway, C., Morgado Ramirez, D.Z., Bhatnagar, T., Oldfrey, B., Morjaria, P., Moulic, S.G., Ebuenyi, I.D., Barbareschi, G., Meeks, F., Massie, J., Ramos-Barajas, F., McVeigh, J., Keane, K., Torrens, G., Rao, P.V.M., MacLachlan, M., Austin, V., Kattel, R., Metcalf, C.D., Sujatha, S., 2021. A review of innovation strategies and processes to improve access to AT: Looking ahead to open innovation ecosystems. Assist. Technol. 33, 68–86. https://doi.org/10.1080/10400435.2021.1970653

Holloway, I., Todres, L., 2003. The Status of Method: Flexibility, Consistency and Coherence. Qual. Res. - QUAL RES 3, 345–357. https://doi.org/10.1177/1468794103033004

Holston, J., Appadurai, A., 1998. Introduction, Cities and Citizenship. Duke University Press.

International Organization for Standardization, 2022. Assistive Products—Classification and Terminology; ISO 9999:2022. Geneva, Switzerland.

Invalid, S., 2017. Skin, Tooth, and Bone – The Basis of Movement is Our People: A Disability Justice Primer. Reprod. Health Matters 25, 149–150. https://doi.org/10.1080/09688080.2017.1335999

Ishida, T., 2002. Digital City, Smart City and Beyond.

James, J., 2013. The Diffusion of IT in the Historical Context of Innovations from Developed Countries. Soc. Indic. Res. 111, 175–184. https://doi.org/10.1007/s11205-011-9989-0

Jenkins, R., 2008. Identity Matters. Soc. Identity Lond. N. Y. Routledge Taylor Francis Group 3–11.

Jones, J., Pal, J., 2015. Counteracting dampeners: understanding technology-amplified capabilities of people with disabilities in Sierra Leone, in: Proceedings of the Seventh International Conference on Information and Communication Technologies and Development, ICTD ’15. Association for Computing Machinery, New York, NY, USA, pp. 1–10. https://doi.org/10.1145/2737856.2738025

Joshi, B., Thomas, B., 2020. Barriers Faced by Persons with Disabilities in Formal Employment in India. Disabil. CBR Incl. Dev. 30, 125–132. https://doi.org/10.5463/dcid.v30i3.823

Jumia, 2019. Nigeria mobile report 2019 [WWW Document]. URL https://www.jumia.com.ng/mobile-report/ (accessed 9.20.19).

Kabeer, N., 2006. Citizenship, Affiliation and Exclusion: Perspectives from the South. IDS Bull. 37, 91–101. https://doi.org/10.1111/j.1759-5436.2006.tb00291.x

Kabeer, N., 2005. Introduction: The search for inclusive citizenship: Meanings and expressions in an interconnected world, in: In N Kabeer (Ed.) Inclusive Citizenship: Meanings and Expressions. London: Zed, 05.

Kafer, A., 2013. Feminist, Queer, Crip. Indiana University Press.

Katsui, H., Kumpuvuori, J., 2008. Human Rights Based Approach to Disability in Development in Uganda: A Way to Fill the Gap between Political and Social Spaces? Scand. J. Disabil. Res. 10, 227–236. https://doi.org/10.1080/15017410802410084

Kett, M., Cole, E., Beato, L., Carew, M., Ngafuan, R., Konneh, S., Colbourn, T., 2021. The Ebola crisis and people with disabilities’ access to healthcare and government services in Liberia. Int. J. Equity Health 20, 247. https://doi.org/10.1186/s12939-021-01580-6

Khasnabis, C., Holloway, C., MacLachlan, M., 2020. The Digital and Assistive Technologies for Ageing initiative: learning from the GATE initiative. Lancet Healthy Longev. 1, e94–e95. https://doi.org/10.1016/S2666-7568(20)30049-0

Khasnabis, C., Mirza, Z., MacLachlan, M., 2015. Opening the GATE to inclusion for people with disabilities. Lancet Lond. Engl. 386, 2229–2230. https://doi.org/10.1016/S0140-6736(15)01093-4

Kohl 3rd, H.W., Craig, C.L., Lambert, E.V., Inoue, S., Alkandari, J.R., Leetongin, G., Kahlmeier, S., 2012. The pandemic of physical inactivity: global action for public health. The Lancet 380, 294–305. https://doi.org/10.1016/S0140-6736(12)60898-8

Komninos, N., 2009. Intelligent cities: Towards interactive and global innovation environments. Int. J. Innov. Reg. Dev. - Int J Innov. Reg Dev 1. https://doi.org/10.1504/IJIRD.2009.022726

Kristiansen, K., Kermit, P., 2007. Disability Rights and Wrongs, Book Review. Scand. J. Disabil. Res. 9, 278–281. https://doi.org/10.1080/15017410701687543

Lamichhane, K., Okubo, T., 2014. The nexus between disability, education, and employment: Evidence from Nepal. Oxf. Dev. Stud. 42, 439–453.

Layton, N., Bell, D., Borg, J., Steel, E., Maclachlan, M., Tebbutt, E., Khasnabis, C., Swaminathan, S., 2020a. Assistive technology as a pillar of universal health coverage: qualitative analysis of stakeholder responses to the world health assembly resolution on assistive technology. Disabil. Rehabil. Assist. Technol. 15, 825–831. https://doi.org/10.1080/17483107.2020.1774929

Layton, N., MacLachlan, M., Smith, R.O., Scherer, M., 2020b. Towards coherence across global initiatives in assistive technology. Disabil. Rehabil. Assist. Technol. 15, 728–730. https://doi.org/10.1080/17483107.2020.1817162

Layton, N., Murphy, C., Bell, D., 2018. From individual innovation to global impact: the Global Cooperation on Assistive Technology (GATE) innovation snapshot as a method for sharing and scaling. Disabil. Rehabil. Assist. Technol. 0, 1–6. https://doi.org/10.1080/17483107.2018.1467971

Lemanski, C., 2022. Afterword: Citizenship and the politics of (im)material stigma and infrastructure. Urban Stud. 59, 663–671. https://doi.org/10.1177/00420980211055301

Lister, R., 2007. Inclusive Citizenship: Realizing the Potential. Citizsh. Stud. 11, 49–61. https://doi.org/10.1080/13621020601099856

Locke, J., 1967. Locke: Two treatises of government. Cambridge university press.

Lorde, A., 1982. Learning from the 60s. URL https://www.blackpast.org/african-american-history/1982-audre-lorde-learning-60s/ (accessed 11.27.22).

Lukes, S., 2005. Power and the Battle for Hearts and Minds. Millennium 33, 477–493.

Macarthy, J.M., Conteh, A., Sellu, S.A., Heinrich, L., Sierra Leone Urban Research Centre, 2018. Health impacts of the living conditions of people residing in informal settlements in Freetown: report on the Future Health Systems (FHS) research in Freetown.

MacLachlan, M., 2019. Access to Assistive Technology, Systems Thinking, and Market Shaping: A Response to Durocher et al. Ethics Behav. 29, 196–200. https://doi.org/10.1080/10508422.2018.1447382

MacLachlan, M., McVeigh, J., Cooke, M., Ferri, D., Holloway, C., Austin, V., Javadi, D., 2018. Intersections Between Systems Thinking and Market Shaping for Assistive Technology: The SMART (Systems-Market for Assistive and Related Technologies) Thinking Matrix. Int. J. Environ. Res. Public. Health 15, 2627. https://doi.org/10.3390/ijerph15122627

MacLachlan, M., Scherer, M.J., 2018. Systems thinking for assistive technology: a commentary on the GREAT summit. Disabil. Rehabil. Assist. Technol. 13, 492–496. https://doi.org/10.1080/17483107.2018.1472306

Maier, Elizabeth, Alvarez, S.E., 2010. Concluding Reflections: Renegotiating Gender in Latin America And The Caribbean, in: Maier, Elizabrth, Lebon, N. (Eds.), Women's Activism in Latin America and the Caribbean, Engendering Social Justice, Democratizing Citizenship. Rutgers University Press, pp. 337–352.

Marx, K., Engels, F., 1948. Manifesto of the Communist Party. International Publishers.

Mazzucato, M., 2015. Building the Entrepreneurial State: A New Framework for Envisioning and Evaluating a Mission-Oriented Public Sector (SSRN Scholarly Paper No. ID 2544707). Social Science Research Network, Rochester, NY.

McRuer, R., 2010. Disability Nationalism in Crip Times. J. Lit. Cult. Disabil. Stud. 4, 163–178. https://doi.org/10.3828/jlcds.2010.13

McRuer, R., 2006. Crip Theory: Cultural Signs of Queerness and Disability. New York University Press, New York.

Meagher, K., 2007. Manufacturing Disorder: Liberalization, Informal Enterprise and Economic ‘Ungovernance’ in African Small Firm Clusters. Dev. Change 38, 473–503. https://doi.org/10.1111/j.1467-7660.2007.00420.x

Milan, S., 2013. Social Movements and Their Technologies: Wiring Social Change. Springer.

Ministry of Health and Sanitation, 2021. Priority Assistive Product List of Sierra Leone. Sierra Leone.

Ministry of Helath and Sanitation, 2021. Assistive Technology Policy Strategy SL. Freetown Sierra Leone.

Mitra, S., 2006. The Capability Approach and Disability. J. Disabil. Policy Stud. 16, 236–247. https://doi.org/10.1177/10442073060160040501

Mladenov, T., 2020. Performativity and the Disability Category: Solving The Zero Theorem. Crit. Sociol. 46, 51–64. https://doi.org/10.1177/0896920518796904

Mladenov, T., 2017a. From State Socialist to Neoliberal Productivism: Disability Policy and Invalidation of Disabled People in the Postsocialist Region. Crit. Sociol. 43, 1109–1123. https://doi.org/10.1177/0896920515595843

Mladenov, T., 2017b. Governing through personal assistance: a Bulgarian case. Scand. J. Disabil. Res. 19, 91–103. https://doi.org/10.1080/15017419.2016.1178168

Mladenov, T., 2016. Disability and social justice. Disabil. Soc. 31, 1226–1241. https://doi.org/10.1080/09687599.2016.1256273

Mladenov, T., 2015a. Neoliberalism, postsocialism, disability. Disabil. Soc. 30, 445–459. https://doi.org/10.1080/09687599.2015.1021758

Mladenov, T., 2015b. Critical Theory and Disability, Critical Theory. Bloomsbury.

Mladenov, T., 2015c. From State Socialist to Neoliberal Productivism: Disability Policy and Invalidation of Disabled People in the Postsocialist Region. Crit. Sociol. 43, 1109–1123. https://doi.org/10.1177/0896920515595843

Monson, T.J., 2015. Collective mobilization and the struggle for squatter citizenship: Rereading “xenophobic” violence in a South African settlement. Int. J. Confl. Violence 9, 39–55.

Moser, I., 2006. Disability and the promises of technology: Technology, subjectivity and embodiment within an order of the normal. Inf. Commun. Soc. 9, 373–395. https://doi.org/10.1080/13691180600751348

Moser, I., 2005. On Becoming Disabled and Articulating Alternatives. Cult. Stud. 19, 667–700. https://doi.org/10.1080/09502380500365648

Moser, I., 2000. AGAINST NORMALISATION: Subverting Norms of Ability and Disability. Sci. Cult. 9, 201–240. https://doi.org/10.1080/713695234

Mosse, D., 2010. A Relational Approach to Durable Poverty, Inequality and Power. J. Dev. Stud. 46, 1156–1178. https://doi.org/10.1080/00220388.2010.487095

Myers, G.A., 2012. Seven Themes in African Urban Dynamics.

Ned, L.Y., Dube, K., Swartz, L., 2022. Challenges and opportunities of centring the African voice in disability research. Afr. J. Disabil. 11, 1089. https://doi.org/10.4102/ajod.v11i0.1089

Normie, L., Gavrish, A., Marincek, C., Buhler, C., Knops, H., Andrich, R., 2001. Market diffusion processes for assistive technology products, in: Assistive Technology - Added Value to the Quality of Life, Assistive Technology Research Series. pp. 701–709.

Nussbaum, M., 2003. Capabilities as Fundamental Entitlements: Sen and Social Justice. Fem. Econ. 9, 33–59. https://doi.org/10.1080/1354570022000077926

Nussbaum, M.C., 2011. Creating Capabilities, Reprint edition. ed. Harvard University Press.

Nussbaum, M.C., 2006. Frontiers of justice : disability, nationality, species membership / Martha C. Nussbaum. Belknap, Cambridge, Mass. ; London.

Nussbaum, M.C., 2001. Symposium on Amartya Sen’s philosophy: 5 Adaptive preferences and women’s options. Econ. Philos. 17, 67–88. https://doi.org/10.1017/S0266267101000153

Oggero, G., Puli, L., Smith, E.M., Khasnabis, C., 2021. Participation and Achievement in the Summer Paralympic Games: The Influence of Income, Sex, and Assistive Technology. Sustainability 13, 11758. https://doi.org/10.3390/su132111758

Oliver, M., 2013. The social model of disability: thirty years on. Disabil. Soc. 28, 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Oliver, M., 1994. Politics and language: Understanding the disability discourse. MA Disabil. Stud. Programme 1994, 1–14.

Oliver, S., 2007. Betty Friedan: The Personal Is Political, 1st edition. ed. Pearson, New York, N.Y.

Opoku, M., Mprah, W., Saka, B., 2017. Participation of persons with disabilities in political activities in Cameroon. Disabil. Glob. South 3, 980–999.

Ossul-Vemehren, I., Julian Walker, Mark Carew, 2022. Assistive Technology in urban low-income communities in Sierra Leone and Indonesia: Rapid Assistive Technology Assessment (rATA) survey results.

Oxfam, 2016. AN ECONOMY FOR THE 1% How privilege and power in the economy drive extreme inequality and how this can be stopped (210 OXFAM BRIEFING PAPER).

Pemunta, N.V., Tabenyang, T.C.-J., 2017. Cultural power, ritual symbolism and human rights violations in Sierra Leone. Cogent Soc. Sci. 3, 1295549. https://doi.org/10.1080/23311886.2017.1295549

Pendall, R., Theodos, B., Franks, K., 2012. Vulnerable people, precarious housing, and regional resilience: an exploratory analysis. Hous. Policy Debate 22, 271–296.

Persson, H., Åhman, H., Yngling, A.A., Gulliksen, J., 2015. Universal design, inclusive design, accessible design, design for all: different concepts—one goal? On the concept of accessibility—historical, methodological and philosophical aspects. Univers. Access Inf. Soc. 14, 505–526. https://doi.org/10.1007/s10209-014-0358-z

Piepzna-Samarasinha, L.L., 2018. Care Work: Dreaming Disability Justice. Arsenal Pulp Press, Vancouver.

Pineda, V.S., 2020. Understanding Disability in Theory, Justice, and Planning, in: Pineda, V.S. (Ed.), Building the Inclusive City: Governance, Access, and the Urban Transformation of Dubai. Springer International Publishing, Cham, pp. 23–45. https://doi.org/10.1007/978-3-030-32988-4_2

Price, J., Goyal, N., 2016. The fluid connections and uncertain spaces of women with disabilities: Making links across and beyond the global south, in: Disability in the Global South. Springer, pp. 303–321.

Prime Ministers Office, 10 Downing Street, FCDO, 2020. Prime Minister announces merger of Department for International Development and Foreign Office. GOV.UK.

Puthenkalam, J.J., 2016. Sustainable Development Goals as New Framework for Development From MDGs to SDGs. 上智経済論集 61, 1–18.

Rauchberg, J.S., 2022. Imagining a Neuroqueer Technoscience. Stud. Soc. Justice 16, 370–388. https://doi.org/10.26522/ssj.v16i2.3415

Rawls, J., 1971. A Theory of Justice, A Theory of Justice. Harvard University Press.

Retief, M., Letšosa, R., 2018. Models of disability: A brief overview. HTS Teol. Stud. Theol. Stud. 74. https://doi.org/10.4102/hts.v74i1.4738

Rohwerder, B., 2018. Disability stigma in developing countries 26.

Roulstone, A., 2016. An Introduction and Overview, in: Roulstone, A. (Ed.), Disability and Technology: An Interdisciplinary and International Approach. Palgrave Macmillan UK, London, pp. 1–41. https://doi.org/10.1057/978-1-137-45042-5_1

Rousseau, J.-J., 1964. The social contract (1762). Londres.

Sackey, E., 2015. Disability and political participation in Ghana: an alternative perspective. Scand. J. Disabil. Res. 17, 366–381. https://doi.org/10.1080/15017419.2014.941925

Sandberg, S., 2015. Lean in-Women, work and the will to lead.

Savage, M., Tyler, N., Seghers, F., Afdhila, N., End Fineberg, A., Frost, R., Holloway, C., Boiten, S., Allen, M., Kejariwala, R., 2019. Applying Market Shaping Approaches to Increase Access to Assistive Technology: Summary of the Wheelchair Product Narrative, in: Proceedings of the GReAT Summit 2019. Presented at the Global Report on effective access to Assistive Technology, WHO, Geneva, Switzerland.

Schindler, S., 2014. Producing and contesting the formal/informal divide: Regulating street hawking in Delhi, India. Urban Stud. 51, 2596–2612. https://doi.org/10.1177/0042098013510566

Sen, A., 2010. The Idea of Justice. Penguin.

Sen, A., 1999. Development as Freedom. Oxford University Press, Oxford, New York.

Sen, A., 1998. Equality of what? Contemp. Polit. Philos. Anthol. 476–486.

Sen, A., 1980. Equality of What? Tann. Lect. Hum. Values I, 197–220.

Sepulveda Carmona, M., Donald, K., 2014. Access to Justice for Persons Living in Poverty: A Human Rights Approach. SSRN Electron. J. https://doi.org/10.2139/ssrn.2437808

Shakespeare, T., 2014. Deepening Disability Justice: Beyond the Level Playing Field. Tikkun 29, 22–23.

Shakespeare, T., 2013. Disability Rights and Wrongs Revisited, 2 edition. ed. Routledge, London ; New York.

Shakespeare, T., 2007. Disability Rights and Wrongs. Scand. J. Disabil. Res. 9, 278–281. https://doi.org/10.1080/15017410701687543

Shakespeare, T., 2004. Social models of disability and other life strategies. Scand. J. Disabil. Res. 6, 8–21. https://doi.org/10.1080/15017410409512636

Shakespeare, T., Watson, N., 2001. The social model of disability: An outdated ideology?, in: N. Barnartt, S., M. Altman, B. (Eds.), Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go, Research in Social Science and Disability. Emerald Group Publishing Limited, pp. 9–28. https://doi.org/10.1016/S1479-3547(01)80018-X

SHM Foundation, 2022. Characterising mobile phone inclusion among Assistive Technology users.

Sins Invalid [WWW Document], n.d. . Sins Inval. URL https://www.sinsinvalid.org (accessed 6.20.21).

Slorach, R., 2019. Mike Oliver: a pioneer for disability rights [WWW Document]. Social. Rev. URL http://socialistreview.org.uk/445/mike-oliver-pioneer-disability-rights (accessed 6.24.21).

Slorach, R., 2015. A Very Capitalist Condition: A History and Politics of Disability, UK ed. edition. ed. Bookmarks.

Slorach, R., 2011. Marxism and disability • International Socialism. Int. Social. URL http://isj.org.uk/marxism-and-disability/ (accessed 6.22.21).

SLUDI, 2018. We Voice 4 Space; a national agenda for the inclusion adn participation of person with disabilities (PWD) in elections and political processes in SL. THE PWD AGENDA. Freetown, Sierra Leone.

SLURC, 2018a. Change by Design; Dworzark Community Area Action Paln. SLURC, Dworzark, Freetown, SL.

SLURC, 2018b. Livelihoods_report_2018_08_16.pdf. Freetown, SL.

Smith, A., Thomas, N., 2012. The politics and policy of inclusion and technology in Paralympic sport: beyond Pistorius. Int. J. Sport Policy Polit. 4, 397–410. https://doi.org/10.1080/19406940.2012.745893

Smith, E.M., MacLachlan, M., Ebuenyi, I.D., Holloway, C., Austin, V., 2021. Developing inclusive and resilient systems: COVID-19 and assistive technology. Disabil. Soc. 36, 151–154. https://doi.org/10.1080/09687599.2020.1829558

Smith, E.M., Toro Hernandez, M.L., Ebuenyi, I.D., Syurina, E.V., Barbareschi, G., Best, K.L., Danemayer, J., Oldfrey, B., Ibrahim, N., Holloway, C., MacLachlan, M., 2020. Assistive Technology Use and Provision During COVID-19: Results From a Rapid Global Survey. Int. J. Health Policy Manag. 0. https://doi.org/10.34172/ijhpm.2020.210

Smith, R.O., 2000. Measuring Assistive Technology Outcomes in Education. Diagnostique 25, 273–290. https://doi.org/10.1177/073724770002500403

Smith, R.O., Scherer, M., Cooper, R., Bell, D., Hobbs, D.A., Pettersson, C., Seymour, N., Borg, J., Johnson, M.J., Lane, J.P., Srinivasan, S.S., Rao, P.V.M., Obiedat, Q.M., MacLachlan, M., Bauer, S., 2018. Assistive technology products: a position paper from the first global research, innovation, and education on assistive technology (GREAT) summit. Disabil. Rehabil. Assist. Technol. 0, 1–13. https://doi.org/10.1080/17483107.2018.1473895

Smith, W.D., Bagley, A., 2010. A miniature, wearable activity/fall monitor to assess the efficacy of mobility therapy for children with cerebral palsy during everyday living, in: 2010 Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC). Presented at the 2010 Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC), pp. 5030–5033. https://doi.org/10.1109/IEMBS.2010.5627079

Snyder, S.L., Mitchell, D.T., 2010a. Introduction: Ablenationalism and the Geo-Politics of Disability. J. Lit. Cult. Disabil. Stud. 4, 113–125.

Snyder, S.L., Mitchell, D.T., 2010b. Cultural Locations of Disability. University of Chicago Press.

Soldatic, K., Grech, S., 2016. Disability and Colonialism: (Dis)Encounters and Anxious Intersectionalities.

Sommerlad, H., 2004. Some Reflections on the Relationship between Citizenship, Access to Justice, and the Reform of Legal Aid. J. Law Soc. 31, 345–368.

Statistics SL, 2017. Sierra Leone 2015 Population and Housing Census Thematic Report on Disabiltiy. Statistics Sierra Leone, Freetwon.

Statistics SL, 2016. Statistics Sierra Leone 2015 Population and Housing Census Summary Of Final Results Planning A Better Future 2 2 3 (Government Report). Statistics Sierra Leone, Freetown, Sierra Leone.

Steinfeld, E., Maisel, J., 2012. Universal design: Creating inclusive environments. John Wiley & Sons.

Stephanidis, C., Salvendy, G., Akoumianakis, D., Bevan, N., Brewer, J., Emiliani, P.L., Galetsas, A., Haataja, S., Iakovidis, I., Jacko, J., Jenkins, P., Karshmer, A., Korn, P., Marcus, A., Murphy, H., Stary, C., Vanderheiden, G., Weber, G., Ziegler, J., 1998. Toward an Information Society for All: An International R&D Agenda. Int J Hum Comput Interact. 10, 107–134. https://doi.org/10.1207/s15327590ijhc1002_2

Stone, D., 1984. The Disabled State.

Stramondo, J.A., 2020. The right to assistive technology. Theor. Med. Bioeth. 41, 247–271. https://doi.org/10.1007/s11017-020-09527-8

Sum, C.M., Alharbi, R., Spektor, F., Bennett, C.L., Harrington, C.N., Spiel, K., Williams, R.M., 2022. Dreaming Disability Justice in HCI, in: CHI Conference on Human Factors in Computing Systems Extended Abstracts. Presented at the CHI ’22: CHI Conference on Human Factors in Computing Systems, ACM, New Orleans LA USA, pp. 1–5. https://doi.org/10.1145/3491101.3503731

Tebbutt, E., Brodmann, R., Borg, J., MacLachlan, M., Khasnabis, C., Horvath, R., 2016. Assistive products and the Sustainable Development Goals (SDGs). Glob. Health 12. https://doi.org/10.1186/s12992-016-0220-6

Thomas, C., 2004. Rescuing a social relational understanding of disability. Scand. J. Disabil. Res. 6, 22–36. https://doi.org/10.1080/15017410409512637

Thomas, P., 2005. Mainstreaming disability in development: India country report. Disabil. Knowl. Res.

Thornberg, R., Thornberg, R., 2012. Informed Grounded Theory 3831. https://doi.org/10.1080/00313831.2011.581686

Tilly, C., 1998. Durable inequality, in: Durable Inequality. University of California Press.

Tomlinson, R., 2017. The Scalability of the Shack/Slum Dwellers International Methodology: Context and Constraint in Cape Town. Dev. Policy Rev. 35, 115–133. https://doi.org/10.1111/dpr.12203

Townsend, A., 2014. Smart Cities: Big Data, Civic Hackers, and the Quest for a New Utopia.

Trani, J.F., Bakhshi, P., Bellanca, N., Biggeri, M., Marchetta, F., 2011. Disabilities through the Capability Approach lens: Implications for public policies. Alter 5, 143–157. https://doi.org/10.1016/j.alter.2011.04.001

Trotsky, L., 1938. The death agony of capitalism and the tasks of the Fourth International: The transitional program. Pathfinder Press.

UN Habitat, 2020. Breaking Cycles of Risk Accumulation in African Cities. Ni.

UNDP, 2022. Sierra Leone | United Nations Development Programme [WWW Document]. UNDP. URL https://www.undp.org/sierra-leone (accessed 11.27.22).

UNDP, 2017. The Millennium Development Goals Report 2015 | United Nations Development Programme.

United Nations, 2021. Report of the thirteenth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities 2020. New York.

United Nations, 2019. United Nations Disability Inclusion Strategy. United Nations.

United Nations, 2015. The Global Goals [WWW Document]. Glob. Goals. URL https://www.globalgoals.org/ (accessed 7.6.21).

United Nations, 2006. Convention on the Rights of Persons with Disabilities (CRPD) | United Nations Enable [WWW Document]. URL https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (accessed 6.5.18).

United Nations (Ed.), 1990. Human development report 1990. Published for the United Nations (New York) Development Programme. Oxford Univ. Pr, New York.

United Nations Development Programme, 2016. Sustainable Development Goals [WWW Document]. UNDP. URL https://www.undp.org/sustainable-development-goals (accessed 11.19.22).

USAID, 2014. Healthy Markets for Global Health: A Market Shaping Primer 65.

Valuable 500, 2022. Home - The Valuable 500 [WWW Document]. URL https://www.thevaluable500.com/ (accessed 11.27.22).

Walker, J., 2022. Disability, Care, and the City, GOLD VI Working Paper Series. United Cities and Local Governments, Barcelona.

Walker, J., Ossul-Vermehren, I., 2021. (Re-) constructing Disability through Research: Methodological Challenges of Intersectional Research in Informal Urban Settlements, in: Inclusive Urban Development in the Global South. Routledge, pp. 167–181.

Walker, J.H., Tebbutt, E., 2022. The informal economy as a provider of assistive technology: lessons from Indonesia and Sierra Leone. Health Promot. Int. daac005. https://doi.org/10.1093/heapro/daac005

Walker, Koroma, Braima, Austina Sellu, Sudie, Rigon, Andrea, 2021. The social regulation of livelihoods in unplanned settlements in Freetown: implications for strategies of formalisation. Int. Dev. Plan. Rev. 1–23.

Walsh, S., Johnson, O., 2018. Getting to Zero: A Doctor and a Diplomat on the Ebola Frontline. Zed Books.

Waning, B., Kyle, M., Diedrichsen, E., Soucy, L., Hochstadt, J., Bärnighausen, T., Moon, S., 2010. Intervening in global markets to improve access to HIV/AIDS treatment: an analysis of international policies and the dynamics of global antiretroviral medicines markets. Glob. Health 6, 9. https://doi.org/10.1186/1744-8603-6-9

Warren, J., 2005. Disabled people, the state and employment: historical lessons and welfare policy. Work. Futur. Disabl. People Policy Soc. Incl. 301–313.

WeThe15, 2021.

White, S., 1996. Depoliticising development: the uses and abuses of participation.

WHO, 2018. WHO fact sheet on assistive technology [WWW Document]. URL https://www.who.int/news-room/fact-sheets/detail/assistive-technology (accessed 5.16.21).

WHO, 2017. WHO | Assistive Health Technology (AHT) [WWW Document]. WHO. URL http://www.who.int/phi/implementation/assistive_technology/en/ (accessed 9.22.17).

WHO, 2016. Priority Assistive Products List (APL). WHO, Geneva.

WHO, 2001. International classification of functioning, disability and health: ICF. Geneva: World Health Organization.

Wickenden, M., 2021. Dont leave us out: disability inclusive participatory research - Why and How?

Wickenden, M., Mader, P., Thompson, S., Shaw, J., 2022. Mainstreaming disability inclusive employment in international development. J. Int. Dev. 34, 933–941. https://doi.org/10.1002/jid.3679

WIPO, 2021. WIPO Technolgoy Trends 2021: Assistive Technology. World Intellectual Property Association, Geneva.

Wobbrock, J.O., 2017. SIGCHI Social Impact Award Talk – Ability-Based Design: Elevating Ability over Disability in Accessible Computing, in: Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems, CHI EA ’17. ACM, New York, NY, USA, pp. 5–7. https://doi.org/10.1145/3027063.3058588

Wood, G., 2003. Staying secure, staying poor: the “Faustian Bargain.” World Dev. 31, 455–471.

World Bank, 2022a. A Landscape Review of ICT for Disability-inclusive Education. World Bank, Washington, DC.

World Bank, 2022b. Macro Poverty Outlook for Sierra Leone (Data). Washington, D.C., United States.

World Bank, 2021. Sierra Leone Country Overview [WWW Document]. World Bank. URL https://www.worldbank.org/en/country/sierraleone/overview (accessed 11.29.22).

World Bank, 2020. World Development Report 2020: Trading for Development in the Age of Global Value Chains (Text/HTML). World Bank.

World Health Organization, 2021. Advancing data collection on Assistive Technology [WWW Document]. URL https://www.who.int/tools/ata-toolkit (accessed 3.9.23).

World Health Organization, 2018. Resolution WHA71.8. Improving access to assistive technology. In: Seventy-first World Health Assembly, Geneva, 21–26 May 2018. Resolutions, decisions and annexes (WHA71/2018/REC/1).

World Health Organization, World Bank (Eds.), 2011. World report on disability. World Health Organization, Geneva, Switzerland.

Appendix A: list of findings

Empirical Chapter	Research Questions	Summary findings and where to locate
6. The Situation of Assistive Technology (AT) - access and definitions	How available is AT? Internationally (6.3) Nationally (6.4) Locally (6.5)	A: AT is absent for approximately 15% of people that need it at all levels. This is a proxy estimate and data is poor. Type and quality of AT are extremely limited in SL. (Section 6.1-6.5) B: There is strong and developing global commitment to AT access with associated programmes and donor commitments which show some evidence of implementation and a need for local contextualisation. (6.3) C: There is a strong and new national commitment to AT access in SL which has not yet had the chance to show implementation. There is a need for engagement with the poorest people and stakeholders. (6.4) D: At local settlement level, autonomous, disability-led settlement members had much better access to AT (70%+) than those in 'mainstream' settlements (15%) where disability identity was often hidden/ ignored. The variety and quality of AT was also better. (6.5)
	How is AT defined? (6.6)	E: AT is most often defined as 'priority-products-plus-services' linked to CRPD (using WHO approach) and the data supports the fact that this is the 'settled understanding' of AT used globally. (6.1-6.6) F: However, in reality the definition of AT is proliferating and so it is more difficult to point to specific products or services as 'in' the category we are interested in. (6.6). Therefore, it becomes even more important to understand the rationale for intervention e.g., *AT for what*?
	Framing AT – AT for what? (6.7)	G: While the WHO approach and link to CRPD were recognised by many, there were no common operational models of (disability) justice, and

		therefore an understanding of the framework ‘for what’ is needed. (6.7)
7. The situation of Disability Justice – understanding and claims	What are the common understandings of DJ? Globally (7.3) Nationally (7.4) Locally (7.5)	H: Global policy frameworks for disability inclusion are based on CRPD; they are strategic but difficult to operationalise. No common disability justice frame is held (7.2-7.3); I: Relatively strong ‘disability equality’ legislation nationally favours a paternalistic model of justice. It is poorly implemented in practise with limited recourse to justice for poor disabled people in reality; Government ‘capture’ of scrutiny bodies such as the National Council of Disabled People (7.4); J: Willingness of community-based organisations of the urban poor to locally address disability justice in creative ways despite lack of resources. Some evidence of early impact (7.5);
	What are the DJ claims of urban poor people in the study? Representation (7.6) Recognition (7.7) Redistribution (7.8) Other (7.9)	K: Representation, Recognition, Redistribution all relevant and valued aspects of justice for urban poor disabled people (7.6-7.8); L: Those urban poor disabled people organised collectively, evidence some recourse to justice through human rights instruments, not accessed by those in mainstream settlements (7.6-7.8); M: Many of the primary claims of poor disabled people are for the basic provisions of life, in common with their nondisabled peers. For those living in urban poverty, precarity functions to side-line disability issues due to the life and death nature of access to the basic necessities of life – water, shelter, food (7.9);
	What is DJ in this context?	N: A disconnect at all levels – global, national, local – between those fighting for disability justice and those fighting for poverty alleviation often results in exclusion of poor disabled people from both (7.10); O: The failure of the DJ claims to connect with justice for the urban poor (7.10).

8. Relationship between AT and DJ	How does AT affect DJ Representation (8.2) Recognition (8.3) Redistribution (8.4) Negative correlations? (8.5)	P: AT is valued and necessary for all aspects of parity of participation, but not sufficient alone (8.2-8.4); Q: However, AT is necessary to include disabled people in claims-making toward a better future (8.2-8.4); R: There is the potential for negative correlations between AT and DJ **if** there is no strong framework for intervention sitting behind AT provision (8.2.8.4);
	What is the relationship between the two? (8.6)	S: DJ is 'the mission', AT is a mechanism (8.5); T: Any model of DJ for urban poor people must also be anchored to their struggle against poverty. Without modelling for precarity the model is not relevant to their daily lives and real choices (8.5); U: Disconnection between DJ and campaigns for poverty alleviation results in 'first steps' action towards each which can pull in opposite directions (8.5); V: Real issues of balance of effort and sequencing between the two (DJ and Urban Poverty) arise (8.5); W: AT is nonetheless strategically significant and can be viewed as a transitional demand for poor disabled people both in justice seeking as disabled people and as people living in poverty (8.5).

	i. Develop opportunities for connections and mutual support between organisation of the urban poor and disabled people's organisations		
Local	ii. Support and funding for community based organisations to continue to develop disability inclusive approaches including representation of DP in activities and leadership		
	iii. Support and funding for organistions of disabled people working locally to engage with urban poverty groups and campaigns including reprentation of urban poor people in activities and leadership		
	iv. Sharing learning and practice through federations nationally and globally		

Appendix B: Policy Recommendations

Internationally, actors could:

- address AT access in mainstream Donor funded programmes (not just targeted disability programmes);
- explicitly connect AT to an operational framework for DJ with a common mission for all actors; Implement a London 2012-style framework of delivery;
- find ways to connect the poverty, AT and DJ agenda's actions and actors to a core framework for intervention with recourse to accountability to those most affected;
- improve coordination and donor support to meet local priorities set locally, as well as international priorities;
- support the national governments to lead interventions in their own countries, working with communities most affected; and
- elevate the voices of the most affected communities to agenda-setting level.

Nationally, actors could:

- address implementation of Disability Act & commitments made under CRPD;
- keep and deliver the new priorities on AT provision, with global support;
- address independence and representation on the National Commission, especially by urban poor disabled people;
- develop opportunities for connections and mutual support between organisation of the urban poor and disabled people's organisations;
- offer funding for community-based organisations to continue to develop disability inclusive approaches including representation of DP in activities and leadership; and
- support funding for organisations of disabled people working locally to engage with urban poverty groups and campaigns including representation of urban poor people in activities and leadership.

Locally, actors could:

- share learning and practice through federations nationally and globally; and
- work together towards justice for all, continuing to push and challenge themselves on inclusion.

Appendix C: Phase 1 Coding Framework

(Appadurai, 2004)

First published in Austin et al, 2021.

Appendix D: Topic Guide Data A

Introduction

AT2030—consent and recording

Reminder of research objectives

Initial questions

Name

Age

Gender

Occupation/Education

Where do you live and with whom?

For how long have you lived in this community?

What AT do you have and use?

Citizenship and the City/State:

Can you describe what it means to you to be a Sierra Leonean—to be a citizen of SL?

What are the basic things a citizen of SL can expect?

What are the basic things a citizen of SL must do?

What activities do you do, as citizen of Sierra Leone?

Do you need, or receive, any help in these activities e.g., from friends/family or assistive technology?

Are there any activities you would like to do but cannot?

Do you think there are any differences for a disabled person in being a citizen of SL, compared to a non-disabled person?

Citizenship and the Settlement:

What makes someone be considered as a community member in this settlement? (Prompts: norms, meetings, development projects, community revenue contribution—is it more than just residency?)

If committees/meetings—Are you involved in any community meetings? Do you attend? Does anyone ever raise disability issues?

Are you a member of any other groups in the community e.g., church/mosque/social?

Are there any differences in the the things a disabled person will be required to do to be considered a community member

Are there any ways that disabled people are able to participate with other disabled people in the settlement? (e.g., groups for disabled people, meetings or informal activities). If no…do you think its would be god to have this type of meeting? Or not necessary? Why?

If someone wanted to raise issues of concern to disabled people in the settlement how would they do that?

If you had the opportunity to raise issues that are important to disabled people, here what are the top issues you would raise with the community/community leaders (or other people identified in 7)?

Participation and voice

Can you tell me about whether /how things have changed in terms of participation for disabled people in the community throughout the time you have lived here?

Where is it that you feel people listen to you and your voice is heard? (e.g., home, school, community, social media?)

Where do you feel most able to be yourself? (translation: to be ‘comfortable’ and ‘feel fine’)

End Questions

Is there anything else you’d like to tell me?

Is there anyone else you think I should talk to?

Is there anything else you’d like to ask about the research?

Appendix E: Topic Guide Data D

AT

- What is your organisations primary motivation for working on AT?
- What are your key goals/ targets?
- What are your success measures for working on AT?

Disability Justice

- What definitions of disability justice are used by your organization?
- How / does AT relate to these frameworks?

DJ and AT

- How do you think AT affects (+/-) disability justice?
- How do you think it affects specific components of DJ of parity of participation+?

Global Policy

- Do you believe there are any gaps in policy and tools in terms of addressing AT access

  …for poor people?

  …as a means to political or collective participation?

  …for access to justice for disabled people

- Are you aware of, or supporting any, policy /programmes intervention aimed specifically at poor disabled people in terms of AT access?
- How is it framed/governed in terms of wider justice?
- Is there anything else you'd like to share?

Appendix F: Topic Guide Data E

- How have things changed in the community since 2019?
- Has anything changed with relation to access to AT?
- How is the community now in terms of disabled people being involved in community activities?
- Have the priorities of the community changed?
- Have the priorities of disabled people in the community changed?
- Last week there was a big global conference on AT (WHO Summit 2021). And one of the global disability leaders said “AT provision has to be given now, together with human support and that what was important was that disabled people were agents leading their own change”. What do you think about that?
- The leaders also said AT access was part of a broader struggle for disability rights. What do you think about that?
- Does AT help you access wealth, income or resources?
- Do you think AT helps you to represent yourself / and your community?
- Does AT help you to feel recognised - to help people ‘see’ you?
- If you had one thing to say to the global community on why AT access is important to you what would you tell them?
- What do you think is necessary in Sierra Leone to ensure that everyone has access to the assistive technology they need?
- What do you think is necessary in Sierra Leone to ensure that disabled people have equality?
- If you had one thing to say about disability rights what would you say.
- Thank you – if there is anything you want to say to me I’m ready to listen now.