

# Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Sierra Leone

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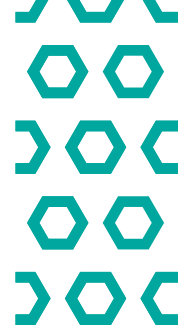


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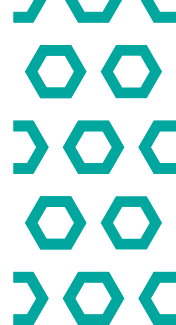
This study was undertaken by Julian Walker, Nada Sallam, and Ignacia Ossul (Development Planning Unit, University College London, DPU-UCL), Samuel Sesay and Ibrahim Gandhi, (CODOHSAPA), Hawanatu Bangura (SLURC), and a facilitation team from FEDURP (the Sierra Leone Federation of the Urban and Rural Poor). Mark Carew (Leonard Cheshire) analysed the rATA survey. Ariana Markowitz (DPU-UCL) edited the final report.

The **Global Disability Innovation Hub** was born out of the legacy of the London 2012 Paralympic Games and launched by Mayor of London Sadiq Khan in September 2016. Its mission is to change how we think about disability through co-design, collaboration, and innovation. GDI Hub provides a platform for the talents of disabled people and the expertise of practitioners, academics, and local communities.

The **Bartlett Development Planning Unit of University College London (DPU)** conducts world-leading research and postgraduate teaching that builds the capacity of national governments, local authorities, NGOs, aid agencies, and businesses working towards socially just and sustainable development in the global south.

The **Centre of Dialogue on Human Settlement and Poverty Alleviation (CODOHSAPA)** is a non-profit and non-governmental organisation established in 2011 to mobilise and provide technical and financial support to its community counterpart, the Federation of Urban and Rural Poor (FEDURP). FEDURP comprises vulnerable women, men, youth, and children who organise around dynamic saving schemes and network at the settlement, city, and national levels to drive collective, bottom-up initiatives. These initiatives promote inclusion and resilience in cities and localities and contribute to national development agendas.

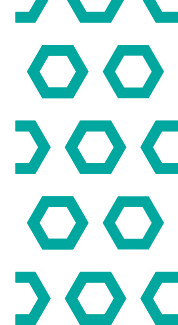
The **Sierra Leone Urban Research Centre (SLURC)**, based in Freetown, is a globally connected research centre created through a partnership between the DPU and the Institute of Geography and Development Studies at Njala University. The centre builds capacity and undertakes research on the wellbeing of residents of informal settlements in cities across Sierra Leone.



**Leonard Cheshire** is a non-profit organisation which has supported disabled people for more than 70 years. In the UK and around the world, Leonard Cheshire works with partners to open doors to opportunity and break down barriers that deny disabled people their basic rights.

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## Executive summary

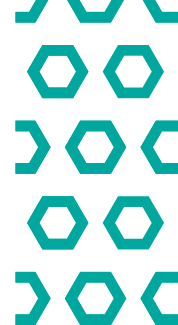
This study was conducted as part of the AT2030 Research Programme, which is funded by the UK Foreign, Commonwealth & Development Office (FCDO) and delivered by the Global Disability Innovation Hub (GDI Hub). It was carried out by a team from the Sierra Leonean Centre of Dialogue on Human Settlement and Poverty Alleviation (CODOHSAPA), the Sierra Leone Federation of the Urban and Rural Poor (FEDURP), the Sierra Leone Urban Research Centre (SLURC), and the Bartlett Development Planning Unit (DPU) at University College London (UCL).

The study supplements the Country Capacity Assessment for Sierra Leone undertaken by the Clinton Health Access Initiative (CHAI), using the World Health Organization (WHO) Assistive Technology Assessment – Capacity (ATA-C) tool, which was developed with support from the GDI Hub. The ATA-C tool assesses the capacity within countries to make the most effective, high-quality assistive technology (AT) available at affordable yet sustainable prices.

The focus of this supplementary informal markets study is to understand existing practices of AT provision through informal markets and social institutions, and the experiences of AT users on low incomes living in informal settlements. We examine how such informal markets can be supported and improved and how formal sector actors working in AT provision can best work with and influence informal AT markets.

The research was conducted in two urban areas: Freetown and Bo. It included data from a household survey that reached approximately 2,000 individuals in the settlements of Thompson Bay and Dwarzarck in Freetown, as well as focus groups discussions (FGDs) with AT users and semi-structured interviews with AT users, Disabled People's Organisations (DPOs), informal and formal AT enterprises, and state stakeholders in the AT sector.

Our study suggests that there is an extremely limited level of AT coverage amongst low-income citizens in Sierra Leone, and that existing formal policy commitments to address AT needs are rarely substantiated in practice, largely due to resource constraints and lack of institutional capacity.

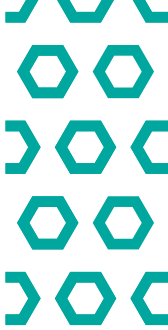


In this context, informal providers—including NGOs, DPOs, and religious organisations—play a key role in providing basic AT. These are formal institutions insofar as most are legally registered as CSOs, but they are informal AT providers since they do not conform with regulations for registering with medical bodies or professional qualifications for staff. In addition, they do not meet minimum AT standards, which is also the case for the formal AT sector in Sierra Leone. Other key informal AT providers are large, usually imported second-hand goods traders and tradespeople such as carpenters and motor mechanics who produce and repair basic assistive products (APs). Again, whilst most of these businesses are formally registered, they are not regulated as AT providers and lack formal skills and knowledge for this role. The final provider is AT users themselves, who operate in a complete state of informality but outside the domain of regulation since their products and services do not pass through AT markets.

Relying on informal providers has a range of disadvantages for those in need of AT. These include providers' inability to produce, prescribe, or fit more complex APs, such as hearing aids or prostheses, issues with the quality of AP, inconsistent supply, and the lack of associated services including training on use. These providers nonetheless remain the principal source of AT for most low-income users and users' relatively high level of satisfaction with informal AT providers, captured in the rATA survey and our focus group discussions (FGDs), reflects advantages of informal AT providers for users: these providers are more widely accessible suppliers; they also more affordable for users who are unable to access free or donated ATs from charities, hospitals, or rehabilitation centres; and they are often more willing or able to customise and fit APs to specific users' needs.

This context raises challenges for efforts to expand access to AT in Sierra Leone:

- How can the benefits of informal AT providers in providing broad and less expensive access to otherwise unserved populations be promoted whilst protecting AT users from unsafe products and services?
- What is a realistic role for under-resourced government agencies in this task?
- How can regulations improve quality without pushing more providers into the informal market, increasing costs, and reducing accessibility?



- In the absence of state capacity for regulating informal AT markets and providers, what other forms of non-state regulation could fill this gap?
- How can more formal and informal private AT providers be encouraged to sell AT consistently and affordably?

In response to these challenges, we highlight recommendations or avenues for future investigation, which we group into two areas: regulation and incentives and knowledge and information sharing.



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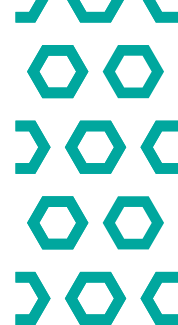
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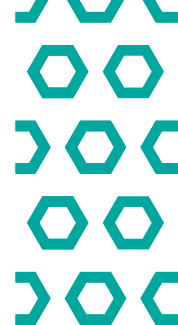
## Acronyms

<b>AfDB</b>	African Development Bank
<b>AP</b>	Assistive product
<b>AT</b>	Assistive technology
<b>ATA-C</b>	Assistive Technology Assessment – Capacity
<b>CODOHSAPA</b>	Centre of Dialogue on Human Settlement and Poverty Alleviation
<b>CHAI</b>	Clinton Health Access Initiative
<b>CPU</b>	Consumer Protection Unit
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>CSO</b>	Civil Society Organisations
<b>DAAG</b>	Disability Awareness Action Group
<b>DP</b>	Disabled people
<b>DPO</b>	Disabled people's organisation
<b>DPU</b>	Development Planning Unit
<b>DRIM</b>	Disability Rights Movement
<b>ETC</b>	Enable the Children
<b>FCC</b>	Freetown City Council
<b>FCDO</b>	UK Foreign, Commonwealth & Development Office
<b>FEDURP</b>	Federation of the Urban and Rural Poor
<b>FGD</b>	Focus group discussion
<b>GATE</b>	Global Cooperation of Assistive Technology
<b>GPS</b>	Global Positioning System
<b>GST</b>	Goods and Services Tax
<b>HAM</b>	Handicap Action Movement
<b>HEPPO</b>	Help Empower Polio Persons Organisation
<b>HI</b>	Handicap International/Humanity and Inclusion
<b>ICRC</b>	International Committee of the Red Cross
<b>ILO</b>	International Labour Organisation
<b>LDS</b>	Church of Jesus Christ of Latter-day Saints
<b>MDCSL</b>	Medical and Dental Council of Sierra Leone
<b>MoE</b>	Ministry of Education
<b>MoF</b>	Ministry of Finance



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<b>MoHS</b>	Ministry of Health and Sanitation
<b>MoSW</b>	Ministry of Social Welfare
<b>MoW</b>	Ministry of Works, Housing, and Infrastructural Development
<b>MSL</b>	Mobility Sierra Leone
<b>NCPD</b>	National Commission for Persons with Disabilities
<b>NaSSIT</b>	National Social Security Insurance Trust
<b>NGO</b>	Non-governmental organisation
<b>NRA</b>	National Revenue Authority
<b>NRC</b>	National Rehabilitation Centre
<b>ODA</b>	Official development assistance
<b>OPD</b>	Outpatient Department
<b>OECD</b>	Organisation for Economic Cooperation and Development
<b>PBSL</b>	Pharmacy Board of Sierra Leone
<b>PET</b>	Personal Energy Transportation Cart
<b>PHDA</b>	Polio Handicap Development Association
<b>PWD</b>	Persons with Disability
<b>rATA</b>	Rapid Assistive Technology Appraisal
<b>SLL</b>	Sierra Leonean Leone (currency)
<b>SLAB</b>	Sierra Leone Association for the Blind
<b>SLSB</b>	Sierra Leone Standards Bureau
<b>SLUDI</b>	Sierra Leone Union on Disability Issues
<b>SLURC</b>	Sierra Leone Urban Research Centre
<b>SSL</b>	Statistics Sierra Leone
<b>TATCOT</b>	Tanzania Training Centre for Orthopaedic Technology
<b>UCL</b>	University College London
<b>UMC</b>	United Methodist Church
<b>UNDP</b>	United Nations Development Programme
<b>UPBSA</b>	United Polio Brothers and Sisters Association
<b>WESOFOD</b>	Welfare Society for Disabled People
<b>WHO</b>	World Health Organization



## 1. Introduction

The purpose of this study is to supplement the Country Capacity Assessments currently being piloted using the WHO ATA-C tool working alongside CHAI with the support of the GDI Hub. The ATA-C tool assesses the capacity within countries to make the most effective, high-quality AT available at affordable yet sustainable prices, and to raise awareness of the steps needed to achieve that goal. It is focused on capacity assessments through Ministries of Health in partnership with other key ministries in the pilot countries.

As defined by the WHO<sup>1</sup>:

- “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.”

This study was conducted as part of the AT2030 Research Programme<sup>2</sup> which is funded by FCDO and delivered by the GDI Hub<sup>3</sup>. Given the limited reach of formal health service interventions in many countries of the global south, including the provision of APs, this study supplements the ATA-C studies with parallel research to understand existing practices of AT provision through informal markets and social institutions, and the user satisfaction and quality of AT for users who have relatively informal citizenship status. The purpose is to determine how informal markets can be supported and improved and how formal sector actors working with AT provision, including Ministries of Health, can best work with and influence informal AT markets to reach citizens who lack formal status.

The focus of this report is on informal markets and access to AT in Sierra Leone, with a particular emphasis on low-income urban citizens. The fieldwork was conducted by FEDURP, SLURC, and CODOHSAPA in partnership with DPU.

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1. See WHO factsheet at <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>  
2. <https://at2030.org/>  
3. <https://www.disabilityinnovation.com/>



## 2. Scope and methodology

Though this project was national in scope, time and resources meant that the research team was only able to undertake fieldwork in two urban sites. These were:

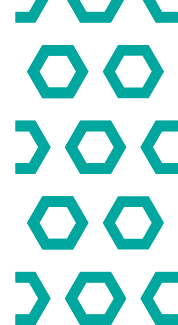
- Freetown, where many of the main stakeholders are based, including, government agencies, NGOs, DPOs, and second-hand shops, and consequently where most services are concentrated; and
- Bo, the location of one of the regional rehabilitation centres and Mobility Sierra Leone (MSL), the largest local producer and provider of AT in Sierra Leone and West Africa.

Whilst we sought to gather a broad, national perspective on AT access using secondary data, the primary research on which this report is based is not representative of the diverse conditions determining access to AT across Sierra Leone, and in particular the experiences of those living in rural areas who are likely to be even more reliant on informal AT providers and services than disabled people (DP) in the two study sites.

## Methods

This study was conducted by a team composed of researchers from FEDURP, SLURC, and CODOHSAPA alongside the DPU. Data collection was through semi-structured interviews and FGDs with a range of stakeholders, a sample survey of AT users in two low-income urban settlements conducted using a smartphone app based on an adapted version of the WHO rATA tool, and analysis of secondary data. These methods are described below and the semi-structured questionnaires and interview guides used are included for reference in Appendix 1.

Interviews and FGDs were undertaken with AT users (and, where relevant, their carers), DPOs, NGOs involved in AT provision and advocacy, formal and informal enterprises involved in AT provision and services, government entities, schools and technical-vocational institutions working with DP, and churches. Table 1 provides a breakdown of interview and FGD participants.



Stakeholder	Activity (Location)	Sub-Group (by impairment)/Specific Organisation	Numbers by gender
AT users	FGD in Thompson Bay (Freetown)	Mobility; visual; hearing; cognitive	8 female 12 male
	FGD in Dwozark (Freetown)	Mobility; visual; cognitive	14 female 12 male
	Interviews with DP in Freetown	Mobility (prosthesis, walking stick, elbow crutches); visual (glass eye, protective glasses)	1 male 1 male 1 male 1 male
			Location
DPOs	Interviews and site visits	Helping Empower Polio Persons Organisation (HEPPO) Sierra Leone Union on Disability Issues (SLUDI) Disability Rights Movement (DRIM) Disability Awareness Action Group (DAAG) MSL Handicap Action Movement (HAM)	Freetown Freetown Bo Freetown Bo Freetown
Government stakeholders	Interviews and site visits	National Rehabilitation Centre Bo Regional Rehabilitation Centre Ministry of Social Welfare (MoSW) National Commission for Persons with Disabilities (NCPD)	Freetown Bo Freetown Freetown
Formal private sector providers	Interviews and site visits	Index Medical and Laboratory Equipment Apex Optics	Freetown Freetown
Informal private sector providers	Interviews and site visits	Carpenter in Brookfields Car repair shop in Brookfields Second-hand shops on Kissy Road	Freetown Freetown Freetown
NGOs	Interviews	Handicap International (HI) Enable the Children (World Hope International) Sightsavers CHAI	Freetown Freetown Freetown Freetown
Schools/technical vocational centres for DP	Interviews and site visits	Cheshire Home Freetown Sir Milton Margai Cheshire Home Bo National School for the Deaf	Freetown Bo Freetown
Religious institutions	Interviews	Faith Healing Church	Freetown

**Figure 1.** Interview and FGD participants



*Sample survey:* A sample survey of AT need and access to AT was undertaken using the WHO rATA tool as part of the AT2030 research programme. Data were collected and stored using KoBoToolbox (<https://www.kobotoolbox.org/>), a suite of tools for data collection and analysis for use especially within challenging environments, with data collection on smartphones. A number of adaptations were made to the original rATA tool, including adding a question on informal providers and ensuring that the skip logic allowed evaluations to be linked to specific APs when respondents used multiple APs.<sup>4</sup> A team from SLURC administered the rATA survey with a team of enumerators from FEDURP.

The surveys were undertaken in two-low income urban communities in Freetown: Thompson Bay and Dwozark. 2,461 individuals were approached to complete the survey, almost evenly split between Dwozark and Thompson Bay (N=1,207 and N=1,254 respectively). Overall, data was collected from 84% of respondents (2,076) who were asked to participate in the survey. Just over 3% of individuals declined to provide consent (79) and consent was not sought where no adults were present (306 households).

*Secondary data:* This research also draws on a range of secondary data including CHAI's 2019 draft report of the ATA-C Country Capacity Assessment and other available national studies.

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4. The rATA tool was modified and trialled by Ignacia Ossul (Development Planning Unit, University College London) and adapted for the Kobo app by Giulia Barbareschi and Cathy Holloway (Department of Computer Science, University College London), and codes were adapted and updated in the field by Wesley Pryor (Nossal Institute for Global Health). Mark Carew (Leonard Cheshire) cleaned the data and performed statistical analysis.



### 3. Informality and AT

We define informal citizenship as, on one hand, the state of lacking the registrations and official recognition that entitles people to the full range of citizenship rights for which they would otherwise be eligible (e.g. the right to social services, legal protection, and democratic participation) and, on the other, the informal connections through which people access their rights and navigate complex bureaucracy.

A key cause of the lack of formal status is residence in informal settlements since, in most contexts, one of the primary factors in determining women and men's citizenship status is the registration of their domicile or place of residence. Informal settlements have been defined (UN, 1997)<sup>5</sup> as:

- Areas where groups of housing units have been constructed on land that the occupants have no legal claim to, or occupy illegally;
- Unplanned settlements and areas where housing is not in compliance with current planning and building regulations (unauthorised housing).

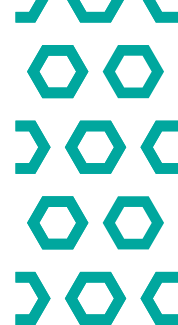
The other area of informality that is central to this study is the informal economy and, specifically, informal enterprise. The key ILO Resolution on informality states that the "... 'informal economy' refers to all economic activities by workers and economic units that are – in law or in practice – not covered or insufficiently covered by formal arrangements".<sup>6</sup> While this definition's focus on lack of formal arrangements seems tautological, the Resolution goes on to clarify that lack of coverage by formal arrangements implies economics activities and enterprises not included in the law, or not covered in practice by the law. The linked term of "informal enterprises" refers to all economic activities or entities that are, in law or practice, not subject to government regulations or insufficiently covered by formal arrangements.<sup>7</sup>

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5. United Nations (1997), Glossary of Environment Statistics, Studies in Methods, Series F, No. 67, United Nations, New York

6. ILO. (2002). Resolution concerning decent work and the informal economy 90th Session of the General Conference of the International Labour Organisation, 2002. Geneva: ILO.

7. Castells, M. and Portes, A. (1989). World Underneath: The Origins, Dynamics and Effect of the Informal Economy in L. Benton et al. The Informal Economy. Baltimore: John Hopkins University Press



We note, however, that although both informal citizenship status and informal enterprise/economy are characterised by an absence of state regulation, in reality there are multiple, overlapping systems of regulation in effect that are partial in their coverage and enforcement. Thus, the idea of a clear dichotomy between formal and informal in which the state is either present or absent in activities or spaces does not hold up well to empirical scrutiny. Both economic sectors and citizens are regulated and registered by different branches of the state. For example, economic activities may be regulated in some ways (e.g. taxation) but not in others (e.g. social protection of workers or quality control of output) and, as we will discuss below, may be characterised by the regulatory presence of some state actors and the absence of others. (See Figure 8 for patterns in Sierra Leone.) ‘Informal’ enterprises and citizens, then, are likely to be regulated and recognised by the state in some ways, but may nonetheless still be considered informal if key gaps in their relationship with the state affect their operations or citizenship entitlements.

In this vein, rather than seeing the distinction between formality and informality as binary, it is more useful to understand it as a “continuum of the reach of official intervention in different economic activities” whilst emphasising that “‘more’ or ‘less’ reach is not necessarily ‘better’ or ‘worse’”.<sup>8</sup> For the purpose of this study, we distinguish between AT markets and citizenship arrangements which tend towards being more or less informal, rather than demarcating a sharp division between the two.

This study explores the relationship between assistive technology (AT) and informality. It was based on the working hypothesis that there are two key linkages between the two.

Firstly, we explore the theory that DP whose citizenship status is relatively ‘informal’ are more likely to be excluded from access to formal AT interventions and systems of distribution because (a) formal state-led AT interventions and policy frameworks require registrations and documentation associated with formal citizenship status, and (b) formal private sector AT is likely to be more expensive and informal citizenship status is highly associated with poverty.

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8. Guha-Khasnobis, B., Kanbur, R., & Ostrom, E. (2006). Beyond formality and informality. Linking the formal and informal economy: Concepts and policies, 4, 75-92. p.1



Secondly, we explore the role that AT delivered by informal enterprises and civil society organisations fulfils in meeting the needs of underserved AT users and people who would benefit from AT. We also assess the pros and cons of informal AT provision. Given the ways in which informality is defined, a characteristic of informal AT providers is that they are unregulated. As such, the capacity of informal AT providers to address unmet need at low cost must be weighed against the danger that unregulated provision could result in low-quality APs that function poorly and could harm users' health and wellbeing. A key concern of this study, therefore, is to explore how the positive capacity of informal AT providers can be nurtured at the same time that the dangers of unregulated AT provision to users can be addressed.

## Informal tenure and citizenship status in Sierra Leone

Informal citizenship is linked to exclusion from state services and protections which are dependent on official registrations and formal tenure. In the case of Sierra Leone, three-quarters of the total urban population lives in areas classified as slums,<sup>9</sup> making exclusion from state services less clear. Indeed, since policies relating to AT access and the enforcement of those policies are significantly lacking, formal rights do little to guarantee access to AT in the country.<sup>10</sup> As an example, whilst the 2011 Disability Act ensures that disabled people have the right to free healthcare, the enforcement of this right at public hospitals is rare, mostly due to hospitals' limited financial resources.

As in other contexts of scarcity, people in Sierra Leone rely heavily on informal connections—referred to as *sababu*, or “those you know”—to access their rights, as well as opportunities, goods, and services. But whilst poverty increases the need for influence, it decreases access to it at high levels,

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9. 2014 Millennium Development Goals Indicator report of the United Nations Statistics Division (2015)

10. The Disability Act (2011) provisioned the issuing of permanent disability certificates, which would enable DP to access all the rights outlined in the Act. This has yet to be implemented however, despite active campaigning on the part of SLUDI. It remains to be seen whether applicants will have to meet any criteria (beyond having a medically-certified disability) that might result in their exclusion, for example, a requirement to produce proof of address or residence in a place if healthcare must be accessed in one's region.



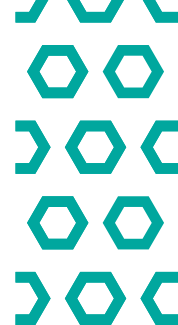
exacerbating exclusion. In addition, the high cost of APs and services that formal stakeholders provide ultimately excludes lower income individuals who are living with informality.

## Informal enterprise in Sierra Leone

In its report on the country's economic characteristics, the government of Sierra Leone defines informal employment as, "the sum of employment in unregistered establishments, unregistered employment in the formal economy and unpaid family workers."<sup>11</sup> According to the most recent census from 2015, self-employment is the most common arrangement in the country, whilst the informal sector employs about 30 percent of the total population—2.2 million people out of 7 million—with women and youth working disproportionately in the informal sector.<sup>12</sup> Though no specific data exists with regards to the number of informal enterprises in Sierra Leone, a 2017 report from the African Development Bank (AfDB), the Organisation for Economic Cooperation and Development (OECD) and the United Nations Development Programme (UNDP) highlights the importance of informal enterprises and stresses the need for interventions to support it, including through vocational training, small and micro enterprise development, and access to credit.<sup>13</sup>

Unlike the limited regulation of people's access to rights through formal citizenship, communities experience the state's reach through its regulation of commercial and non-commercial enterprises. Most businesses such as second-hand shops and tradespeople (including carpenters and car repair shops) that engage informally in the AT and AT service sector are registered with the district councils and the National Revenue Authority (NRA). Local

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11. Statistics Sierra Leone (2017), Sierra Leone 2015 Population and Housing Census. Thematic Report on Economic Characteristics, p. 4-5, Freetown, Sierra Leone: Statistics Sierra Leone. [https://www.statistics.sl/images/StatisticsSL/Documents/Census/2015/sl\\_2015\\_phc\\_thematic\\_report\\_on\\_economic\\_characteristics.pdf](https://www.statistics.sl/images/StatisticsSL/Documents/Census/2015/sl_2015_phc_thematic_report_on_economic_characteristics.pdf)
  12. Statistics Sierra Leone (2016), Sierra Leone 2015 Population and Housing Census. Final Report, Freetown, Sierra Leone: Statistics Sierra Leone. [https://www.statistics.sl/images/StatisticsSL/Documents/final-results\\_-2015\\_population\\_and\\_housing\\_census.pdf](https://www.statistics.sl/images/StatisticsSL/Documents/final-results_-2015_population_and_housing_census.pdf)
  13. AfDB/OECD/UNDP (2017), African Economic Outlook 2017: Entrepreneurship and Industrialisation, p. 9 <https://www.oecd.org/dev/african-economic-outlook-19991029.htm>

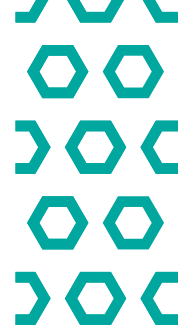


non-commercial entities engaged in AT provision and services, including DPOs, must register with the MoSW and the district councils in order to access state services. Registering with public authorities costs money, paid in the form of an initial registration fee and annual renewal fees, which in some instances places formalisation beyond their reach.<sup>14</sup> State authorities, including the police force and fire brigade, actively enforce public safety laws, both fining and arresting business owners based on the type of violation. They are also alleged to exploit their authority to harass businesses and demand bribes (colloquially termed cold water).

The regulation of AT and AT services is characterised by both over-regulation and under-regulation. On one hand, formal commercial providers encounter numerous and costly registrations that disincentivise formal business participation in the sector and the formalisation of informal providers. At the same time, there is no regulation or enforcement of quality standards for locally produced or imported AT or AT services.

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14. For example, one of the DPOs in Freetown has registered with the Freetown City Council (FCC) but not with the MSW which it argues is too expensive to do.



## 4. Population

The primary source of information on the prevalence of disability in Sierra Leone is the 2015 Population and Housing Census, conducted by Statistics Sierra Leone (SSL), and used as the basis for planning and policymaking. According to the accompanying thematic report,<sup>15</sup> more than 93,000 people in the country, or 1.3% of the population, have a disability. This is split almost evenly between male and female (54% to 46%), with a large portion of them between the ages of 20 and 50 (45%). Far more reside in rural than in urban areas (67% to 33%), and many are neither educated nor employed (63% and 44%, respectively). The distribution of disability types that the census charts (see Figure 2 below) indicates that the most common disability type is physical (mobility) impairments, followed by visual impairments.

	Both sexes	%	Male	%	Female	%
Physical disability (polio)	20 345	21.8	11 255	12.1	9 090	9.8
Physical disability (amputee)	8 305	8.9	4 890	5.3	3 415	3.7
Blind or visually impaired	11 650	12.5	6 799	7.3	4 851	5.2
Partially sighted	14 184	15.2	7 517	8.1	6 667	7.2
Deaf	6 313	6.8	3 089	3.3	3 224	3.5
Partially deaf	4 734	5.1	2 279	2.4	2 455	2.6
Speech difficulties	3 604	3.9	2 010	2.2	1 594	1.7
Mute	3 264	3.5	1 708	1.8	1 556	1.7
Mental difficulties	4 376	4.7	2 393	2.6	1 983	2.1
Spinal injury/disability	2 869	3.1	1 609	1.7	1 260	1.4
Psychiatric disability	1 285	1.4	646	0.7	639	0.7
Epileptic	2 261	2.4	1 168	1.3	1 093	1.2
Rheumatism	1 556	1.7	637	0.7	919	1.0
Albinism	501	0.5	267	0.3	234	0.3
Kyphoscoliosis (Hunch Back)	669	0.7	347	0.4	322	0.3
Other	7 213	7.7	3 705	4.0	3 508	3.8

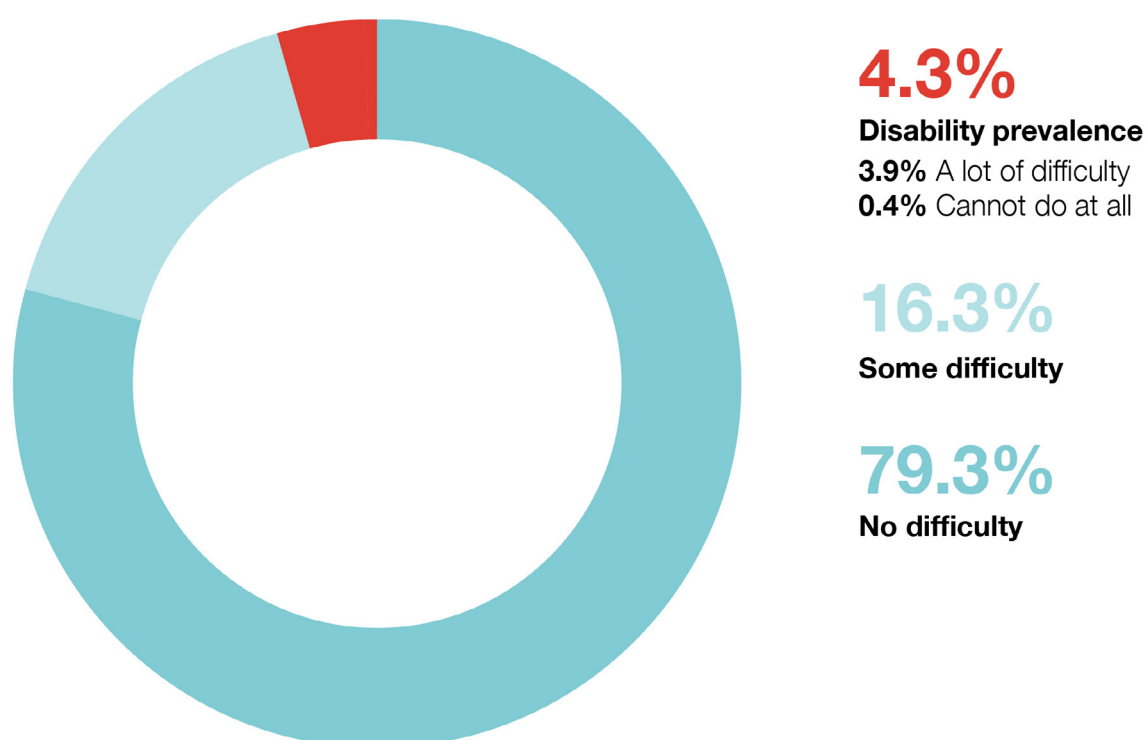
**Figure 2:** Count and percentage distribution of type of disability prevalence by domain and sex from the 2015 census<sup>16</sup>

15. Kabia, Francis and Umaru Tarawally (2017), Sierra Leone 2015 Population and Housing Census. Thematic Report on Disability, Freetown, Sierra Leone: Statistics Sierra Leone <https://sierraleone.unfpa.org/sites/default/files/pub-pdf/Disability%20Report.pdf> (Last accessed 05/01/2020).
16. Kabia, Francis and Umaru Tarawally (2017) Sierra Leone Population and Housing Census 2015: Thematic Report on Disability, Statistics Sierra Leone.



Though the government's report represents the most comprehensive overview on disability, stakeholders criticise it, charging that it grossly underestimates the true prevalence of disability in the country. Underreported numbers, poor data collection methods, and limited coordination between actors means that there is no reliable source of data. Research by NGOs and academic institutions does not cover the national scale, and data is rarely updated frequently enough to remain relevant. According to government actors, the MoSW, NCPD, UNDP, and SLL have begun planning for another study to update the current one.

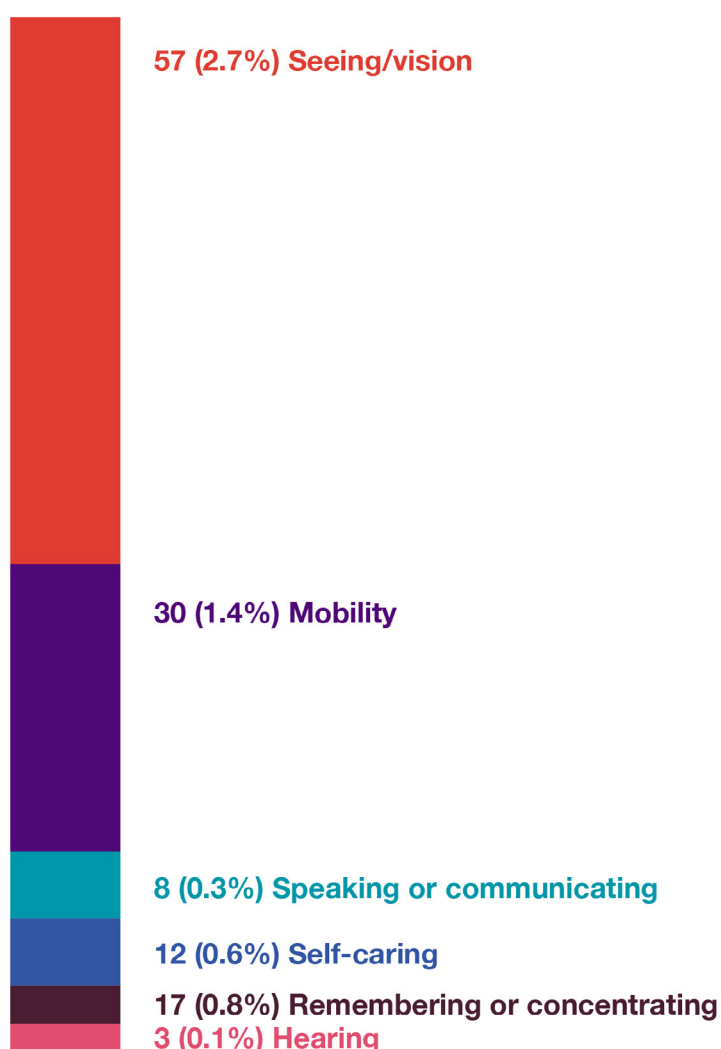
There is no comprehensive source of data on the availability and use of AT in the country. This is in large part a result of, and a contributor to, limited state strategic planning for AT provision. In addition, given that some of the main providers of AT are non-state actors, databases are often maintained on an organisational basis and rarely shared externally. In the absence of national data, the rATA report we conducted acts as a sample survey which gives insights into patterns of AT use in two low-income, informal urban communities.



**Figure 3.** Disability prevalence (respondents answering 'a lot of difficulty' or 'cannot do at all' for any one or more domains) in Thompson Bay and Dwozark (rATA Survey)



Figure 3 shows the percentage of people expressing disability (interpreted as people who report a lot of difficulty or cannot do at all) in the different functioning domains.<sup>17</sup> The most common of these domains is related to seeing and vision (2.7%) followed by mobility (1.4%) (see Figure 4). The total disability prevalence (i.e. the number of people with disabilities) is 4.3%, or 91 people. This is lower than the instances of disability in relation to all of the six domains (5.1% of the total sample) because 0.8% of the sample reported multiple disabilities (i.e. across more than one functioning domain).



**Figure 4:** Disability by functioning domain (respondents answering ‘a lot of difficulty’ or ‘cannot do at all’ in any domain) in Thompson Bay and Dwozark (rATA survey)

17. The rATA survey asks people to report their current level of difficulty in each domain without using any AP (including glasses). This differs from the normal application of the Washington Group questions to identify disability prevalence, which asks people to report their level of difficulty despite using (for the vision domain) glasses (in recognition that these are a widely available AP).

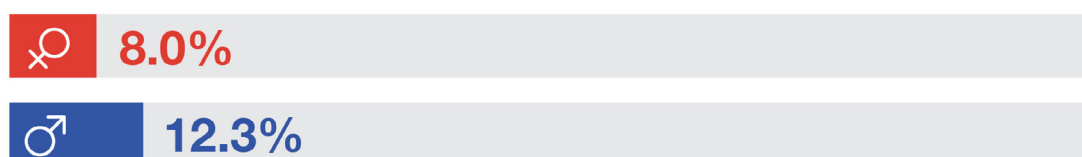


The rATA survey prevalence of 4.3% seems low—a rATA survey conducted with 2,046 residents of low-income settlements in Banjarmasin, Indonesia found a disability prevalence of 7%, for example—but our wider fieldwork suggests possible explanations. Firstly, there is a high level of job seeking migration to Freetown, and it is likely that most of these people are not disabled. In addition, access to health services is poorer in rural areas. Together these could mean that urban settlements have a higher proportion of non-disabled residents. The 2015 Population and Housing Census seems to support this, finding that 67% of DP live in rural areas versus 33% in urban areas, despite that 59% of the total population live in rural areas versus 41% in urban areas.

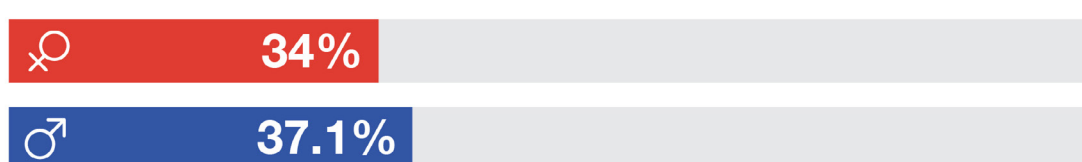
Another possible explanation for this relatively low disability prevalence is that many DP in Freetown live in defined communities of people with disabilities in specific areas of the city rather than in ‘mainstream’ low-income communities such as Thompson Bay and Dwozark. The HEPP0 occupation in Brookfields, for example, is made up of around 50 households headed by people who have had polio, and there is a large and well-known community of disabled street dwellers living in the city centre. This is because DP often leave or are pushed out of their households due to the high level of stigma associated with disability and the lack of livelihood opportunities for DP in residential settlements pushes them to move to commercial centres and engage in begging. Disabled children may move to residential schools for children with disabilities such as the Cheshire Home or St Joseph’s School for the Hearing Impaired in Makeni.



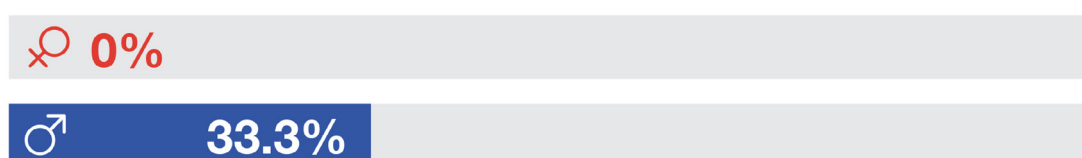
### Some difficulties



### A lot of difficulties



### Unable to do



**Figure 5:** Unmet need by level of difficulty in Thompson Bay and Dwozark (rATA survey)

In addition to giving an indication of the overall prevalence of disability and prevalence across functioning domains, the rATA survey also measures whether participants need an AP that they do not have (see Figure 5). Our survey indicates a very high level of unmet need based on the number of respondents experiencing some difficulty or above in any of the six domains, which aligns with the limited systems for AT provision to low-income citizens that we describe in this report. Specifically, almost one-third of individuals report some difficulty (28.7%; N = 97), four-fifths of individuals report a lot of difficulty (80.5% N = 66) and all of the participants who reported cannot do at all (100%; N = 9) in any one domain had unmet need. This highlights how unmet need for AT increases for those at greatest risk of exclusion from society. The only two domains in which some respondents did not indicate unmet need were mobility (32%) and vision (12.8%), which is consistent with the findings of APs in use in the communities, all of which referred to products related to either mobility or vision. Four-fifths of participants with an unmet need cite lack of affordability as the explanation (N = 140; 80.5%).



## 5. Products and services

We begin this section by looking at how our disabled respondents understand AT and explore the impact that AT has on their lives and wellbeing. We then turn to the AT and AT services that low-income Sierra Leoneans use most often or would like to use. Finally, we look at AT users' qualitative assessment of their AT.

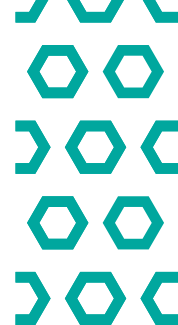
### User perspectives on AT in Sierra Leone

As the data above suggests, access to AT in Sierra Leone is very limited, with availability, awareness, and affordability being the main barriers, particularly for the rural and urban poor. In this context of scarcity, perceptions of what constitutes an AP include many of the things that facilitate DP's day-to-day lives and grant them some degree of independence. This wide definition of APs is also reflected in the official government definition,<sup>18</sup> but only partially overlap with the WHO's list of 50 Priority APs or the 25 APs used as a reference point in the rATA survey. Participants in our research were not familiar with many of the APs in the WHO lists and the products and tools they identified as key in supporting their day-to-day functioning often go beyond products specifically designed to address the needs of DP. In fact, many of our respondents highlighted the importance of a diverse range of generally available products not developed specifically for disabled users, including TVs and footballs.

Products or devices that ease movement—allowing people to travel farther, faster, and more comfortably—are important across disability types. This includes standard APs as well as okada (motorbikes) and kekeh (motorised tricycles) which enable access to services and facilities within respondents' settlements and throughout their respective cities.

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18. The Sierra Leone Disability Act of 2011 defines "assistive devices and services" as "carers, implements, tools and specialized services provided by people to persons with disability to assist them in education, employment or other activities" (Section 1).



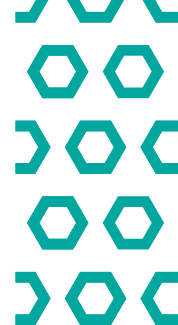
Mobile phones are another important enabler, though there was little familiarity with or use of specific apps designed as AT, such as screen readers for the blind. Instead, respondents highlight the importance of communicating with and staying connected to those they knew, stating that AT allow them to “call their people.” For people with visual and mobility impairments, phones enable asking for help or directions, whilst permitting users the independence of going out alone. Similarly, having access to GPS apps is important to both those with mobility impairments, because the apps reduce or eliminate unnecessary movement, as well as those with visual impairments, for whom GPS apps’ audio feature is key. For those with hearing impairments, phones are a tool for communication, allowing them to send messages to people they know and type out messages to communicate with others in public.

Crucially, though all APs are seen as enablers, some respondents differentiate between them according to the extent to which they feel empowered. For example, though crutches enable movement, they also signal to others that the user is disabled. Given the continued stigma surrounding disabilities in Sierra Leone, including negative assumptions regarding the ability of DP to live and work independently, prostheses, which can be hidden away, provide some users with confidence knowing that others will not behave differently towards them.

Finally, DP frequently describe other “people,” including family, friends, and neighbours, as the biggest source of support in the short and long term.

## **AT and AT services that users most often use or would like to use and qualitative assessments of APs**

This section outlines the most commonly used APs in use. It is important to note from the outset that, where APs do exist in Sierra Leone, they are often poor quality and/or inappropriate for their users. Moreover, as a result of limited exposure, many respondents do not identify APs beyond the ones they have encountered or used. As a result, in most instances, low-income respondents flag the need for better fitting and better quality versions of the products they currently use or previously used.



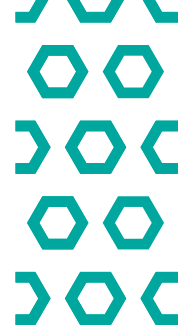
		Private facility / hospital clinic	Non-Govt. Non-profit facility / Charity	Informal sector	Home-made	Govt. facility / public hospital	Formal sector / Business
3	Axillary / elbow crutches					100%	
2	Canes / sticks, Tripod and quadripod	50%			50%		
1	Incontinence products, absorbent						100%
2	Manual wheel-chairs – basic type for active users	50%					50%
1	Manual wheelchairs - push type		100%				
1	Rollators and walking frames					100%	
52	Spectacles	15.4%	5.8%	34.6%		26.9%	26.9%
1	Therapeutic footwear			100%			
2	Other			50%	50%		

**Figure 6:** APs in use by type and provider type in Thompson Bay and Dwozark (rATA survey)

Figure 6 lists the APs in use amongst our survey population by provider type. These represent a small number of the WHO's 50 Priority APs and address only to visual or mobility impairments, despite that participants also report disabilities related to hearing, self-care, communication, and remembering/concentration. Glasses or spectacles emerge as the most widely used AP in the survey, perhaps because visual disabilities are the most frequently reported disability (2.7% of respondents/57 people) or because glasses are a relatively cheap AP that is widely available without a prescription from street traders and at informal markets.

Beyond the rATA survey, our fieldwork picked up other APs commonly in use amongst low-income DP, which we describe below.

**Wheelchairs and Personal Energy Transportation Carts (PETs).** The wheelchairs and PETs in Sierra Leone come from local and international sources, with some imported and assembled and others produced



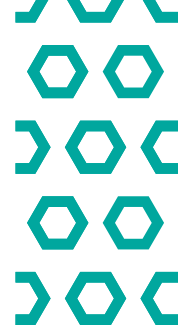
domestically. As low-income users cannot afford to purchase these APs, the vast majority are distributed free of charge, but many users express dissatisfaction with their quality and appropriateness. NGOs and faith-based charities, in particular the Church of Jesus Christ of Latter-day Saints (LDS), donate wheelchairs and PETs to the government, which distributes them through national and regional rehabilitation centres, whilst local and international organisations distribute others directly. Users typically receive fitted wheelchairs that accommodate their specific needs and physical condition with rehabilitation centres maintaining a database of wheelchair serial numbers and users' names to prevent resale. The limited supply through these sources, however, means that many other users access wheelchairs informally through personal networks, or *sababu*: gifts or hand-me-downs from friends and family, including sometimes receiving a deceased person's AP; churches, particularly at the time of religious festivals; and shipments from people in the diaspora. Luck also plays a part in access, for example, being in the street when a church is making a donation. When the need is urgent and some money is available, users may visit second-hand shops selling imported—and, in some instances, stolen—wheelchairs. Though the cost of these wheelchairs is roughly 5% of a new one (SLL 200,000–500,000 SLL or USD 20–30 versus SLL 3–5 million or USD 300–500), this is still beyond the reach of many people.

The vast majority of wheelchairs accessed through informal means are not customised or fitted to the user, which can aggravate injuries and exacerbate pain and discomfort. They may also be old or of poor quality and thus neither durable nor built to withstand the local terrain and topography. Repairing wheelchairs presents another set of challenges, as spare parts are unavailable locally or no longer produced in the case of older wheelchairs. In response, many users learn how to repair their own wheelchairs and support those that do not or cannot. Replacing spare parts often involves improvising, including buying parts from motorcycle shops, car repair shops, and welders. Wheelchairs acquired through the rehabilitation centres or DPOs, on the other hand, can normally be taken for repairs. In the case of PETs, the single biggest source in the country is MSL, a local organisation based in Bo that produces, assembles, and distributes mobility devices.



**Crutches (elbow/shoulder) and walking sticks.** DP access most crutches and walking sticks through the same sources that supply wheelchairs. When available, public hospitals provide patients with crutches or refer them to rehabilitation centres. Due to limited supply, access is on a first-come-first-served basis, but respondents describe learning that crutches were ‘reserved’ for other patients, indicating the role of sababu in AP access. Though government regulation forbids public hospitals from selling crutches and wheelchairs, several respondents refuted this claim. Donations through NGOs and charities also play a significant role in the provision of crutches, with supplies coming from international organisations, churches, and the Sierra Leonean diaspora. As with wheelchairs, many of these crutches are used and of poor quality. Similarly, second-hand shops are an alternative informal source of crutches, but many users still cannot afford the cost, plus crutches are not always sold in pairs. Walking sticks are most often self-made or commissioned at a carpentry shop, with users explaining that these are more durable than what they can acquire through formal means as well as being easier to use since they are customisable. Whilst some sticks are made of steel, most are made of wood with small metal plates screwed into the base to reduce slipping and wear and tear. The component of crutches that most frequently needs to be repaired or replaced is the rubber tip, which most users replace at car repair shops using old tyre parts, which they find to be more durable than the original. Mobility Sierra Leone produces tips (soles) using polypropylene, but they are expensive since they use material imported from abroad, so demand is limited.

**Prostheses and calipers.** Both prostheses and calipers are in high demand as a result of the civil war (1991–2002), the prevalence of debilitating diseases such as polio, and various types of accidents. Though supply is extremely limited, the primary source for low-income respondents is hospitals and rehabilitation centres. In most instances, users are referred by the hospitals where they receive treatment (most often amputation) to the national and regional rehabilitation centres where the country’s few trained specialists offer fitting and rehabilitation services. Users are measured and fitted for their prosthetic limb, sent to physiotherapy, and trained on the use and maintenance of their prosthesis. At the moment, however, a severe shortage in both good quality prostheses and the materials needed to produce and assemble them means that most centres are either unable to provide them or



are forced to dismantle old prostheses and refit them for a new user using a variety of materials and techniques. As a result, the prostheses are not up to technical standards and their durability and functionality are poor. The LDS provides most donations of new supplies. Services and APs that rehabilitation centres provide are supposed to be free of charge, but respondents describe paying for both fitting and replacement. Rehabilitation centres offer repairs free of charge, but their ability to undertake this work is often hampered by the lack of available materials. The FT Stocco Hospital in Makeni also provides prostheses, but, similar to the rehabilitation centres, faces a shortage of materials, trained staff, and up-to-date functioning machinery. A private Catholic hospital in Masanga provides calipers at a lower price than the government's centres according to some respondents, and also offers physiotherapy, though not rehabilitation, to patients. In addition, this hospital is the only one with a 3D printer which it has used to make prosthetic arms. The final key source of prostheses and calipers in the past was Mercy Ships, an international NGO providing medical services from a ship, which made five trips to Sierra Leone between 2001 and 2011. All Mercy Ships services were free of charge, but APs were provided on a first-come-first-served basis. Mercy Ships also established a land-based centre in Waterloo in 2000 offering rehabilitation services, but limited demand led to the centre's closure.

**Glasses and sunglasses.** Glasses and sunglasses are crucial for those with visual impairments and albinism, though most respondents complained about poor quality. Glasses can be purchased from most hospitals and optical shops, where eye tests, prescriptions, and other associated services are also administered, but these formal providers are often too costly for low-income users and tests are rarely offered for free. Instead, users often purchase glasses and sunglasses from second-hand shops and street traders, testing different pairs until they find one they deem suitable. Sometimes referred to as "Chinese glasses," these normally cost one-tenth of the price of a pair purchased through a formal provider, but they also tend to be of poorer quality and many respondents complain about their durability and the worsening effect they have on their eyesight. The preferred providers—despite that their AT provision is neither reliable nor consistent—are NGOs and charity-based eye clinics which charge nominal fees (if any) for consultations and tests, and provide high-quality, prescription glasses to users for free, usually through campaigns and project interventions.



**White canes.** The main source of white canes is the Sierra Leone Association for the Blind (SLAB), which relies on donations from international charities and then distributes them to individuals and DPOs. Its main provider in the past was Sightsavers, an international charity working to prevent blindness and advocate on behalf of DP. SLAB also receives donations from DPOs and state actors, including the NCPD. Government rehabilitation centres provide white canes that primarily come from the LDS, which users can obtain with referrals from hospitals and DPOs, but users criticise these APs for their poor durability.

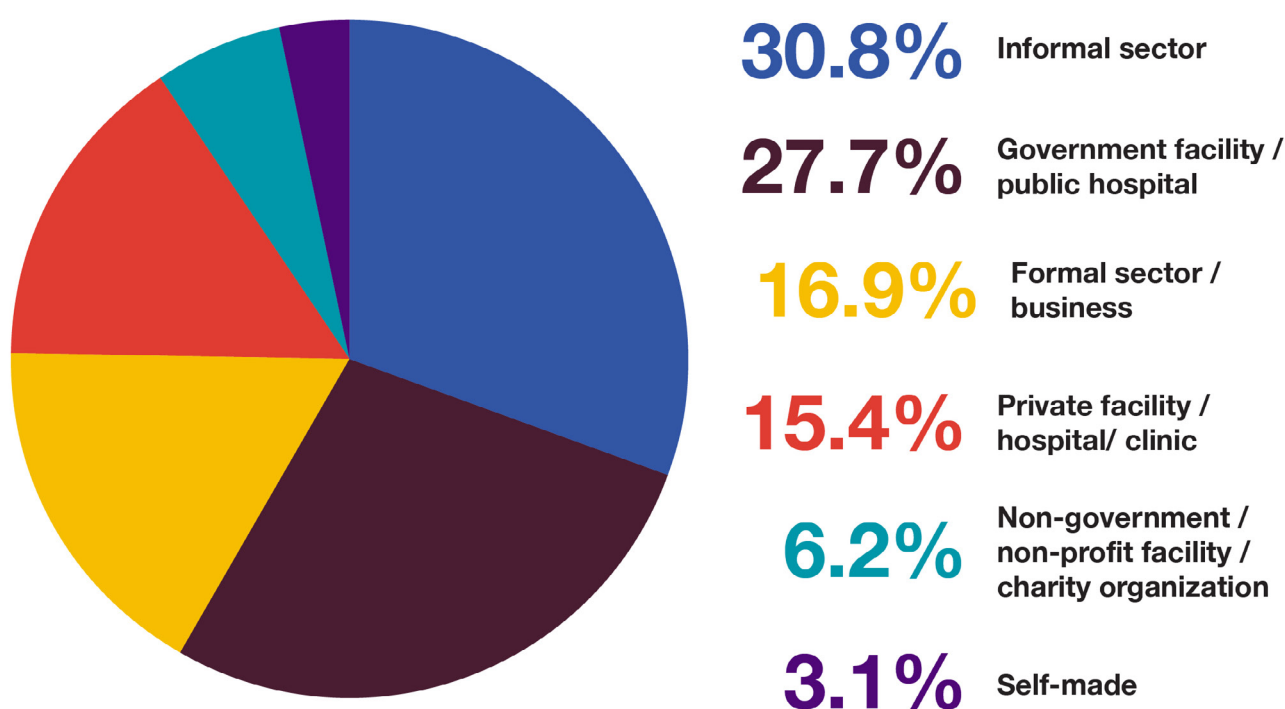
**Hearing aids.** Though not useful for those with severe hearing loss, hearing aids are an important AP for people with limited hearing impairments. With a single hearing aid costing upwards of SLL 1 million (USD 100), however, most users must rely on donations. The most frequently cited source of hearing aids is St Joseph's School for the Hearing Impaired run by the Catholic mission in Makeni. The school receives donations from individuals abroad as well as from local and regional organisations, and distributes them to users and DPOs. With an in-house audiology specialist, the school administers tests and fittings for hearing-impaired school children around the country and conducts quality checks on products. These quality checks are crucial as respondents describe the poor quality of hearing aids donated from other sources, which often make noise and overheat, causing severe discomfort to the user. The National School for the Deaf in Freetown notes that the government does not yet distribute hearing aids and that the subsidy that the Ministry of Education (MoE) provides to the school is neither sufficient nor reliable enough to purchase AT. Lastly, international NGOs such as Soundseekers, a UK-based organisation supporting the empowerment of hearing-impaired people in Africa, provided hearing aids to Sierra Leone in the past, though it is unclear to what extent this still occurs. Neither second-hand shops nor the sole formal medical supply shop in Sierra Leone sell hearing aids, which are instead ordered from abroad by ENT specialists on the basis of need.



## 6. Stakeholders and their roles

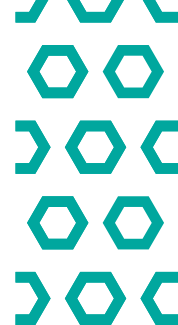
### Stakeholders involved in AT and AT service provision to informal residents or low-income AT users and the differences between AT from official and 'informal' sources

A range of stakeholders are involved AT programming, including more formal state institutions and private businesses and less formal church groups, DPOs, and semi- or unregistered small businesses and traders. This section gives an overview of some of these stakeholders, their roles, and their level of coverage.



**Figure 7:** Sources of AP in Thompson Bay and Dwozark (rATA Survey)

In the absence of national-level quantitative data on AP use and sources, the only dataset we are able to draw upon was the rATA survey. We define 'informal providers' for the rATA as unregistered providers, including second-hand shops, markets, and street traders, without expertise in AP prescription or provision, which differentiates them from 'homemade,' the other informal source of AP. As Figure 7 illustrates, in the two settlements surveyed, informal providers are the largest source of APs, followed closely by government



facilities and public hospitals, but the reality is more complex as different aspects of AP and AP services are often provided in by a combination of different providers.

Firstly, whilst the rATA survey distinguishes between government (27.7%) and private (15.4%) medical facilities, users are normally required to pay for services at both government and private medical facilities, making the difference between the two moot. Indeed, users tend to rank hospitals by their affordability rather than whether they are public or private.

Secondly, the prominence of informal providers as a source of AP reflects the overrepresentation of glasses and spectacles, most often sold in second-hand shops and by street traders (see Figure 6 above). In contrast, other APs that come up less frequently in the survey are from other types of provider types. For example, the one wheelchair in the survey is from an NGO and the three crutches all come from public hospitals.

Finally, the distinction that Figure 7 draws between formal and informal providers is further complicated by our finding that some of the more ‘formal’ providers, including government providers such as the National Rehabilitation Centre (NRC) and some NGOs, at times acquire the APs that they distribute from second-hand informal providers, such as traders on Kissy Road. We explore this more complex picture of formal and informal AP providers and the relations between them below.

## Formal state stakeholders

Several government ministries, especially the **Ministry of Health and Sanitation** (MoHS), and the **MoSW**, are tasked with tackling issues pertaining to DP. The MoHS, through its Directorate of Non-Communicable Diseases and Mental Health, is mandated with handling AP service provision, including “the development, financing and implementation of AT services; the development of standards for AT products, procurement and user-assessments; and the provision of pre-service and in-service training for AT cadre.”<sup>19</sup> The

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19. CHAI 2019, ATA-C, Freetown.



MoSW, though not directly involved in the provision of AT and AT services, is responsible for “ensuring the inclusion of disability issues in all social development agendas; and leading all welfare campaigns and activities.”

Working alongside them is the **NCPD**, a statutory body established by the 2011 Disability Act to ensure the rights and privileges of all DP. The NCPD is charged with “advising on, and regulating the implementation of policies and provisions committed to by the government; conducting disability audits and preparedness assessments” and maintaining a database of all disabilities in the country, as well as managing all “institutions, associations and organisations, both public and private, that provide services for the rehabilitation and welfare of persons with disability” (Disability Act, 6(2) i.ii). With regards to AT, the NCPD has been tasked with “provid[ing] as far as possible ... assistive devices, appliances and other equipment to persons with disability” and “access to available information and technical assistance to all public and private institutions, associations and organizations concerned with persons with disability” (Disability Act, 6(2) j.i and j.ii). In addition, the Disability Act established a fund for the NCPD to use to “provide or contribute to the cost of assistive devices and services” (Disability Act, 31(4) d), which we describe in more detail below. Despite good intentions, however, limited resources and capacity mean that most government agencies cannot meet their mandates. This has a disproportionate impact on low-income AT users who are more likely to depend on free public services.

The **national and regional rehabilitation centres**, initially established and run by Handicap International (HI) and often still referred to as such, represent the main state-supported source of AT and AT services, as well as of medical services including physiotherapy and rehabilitation. Operating in three cities—Freetown, Bo, and Koidu—the centres provide assembly, fitting, training, distribution, and repair services for wheelchairs, crutches, white canes, and prostheses. Despite employing most of the highly trained professionals in the country, however, limited financial support from the state means that both the production and provision of AT and AT services is greatly reduced. This is particularly true for prostheses, which the centres are no longer able to produce due to a shortage of materials; polypropylene, which is a core component of the ICRC process for which the centres are equipped, must be imported. As a result, the centres mainly repurpose second-hand

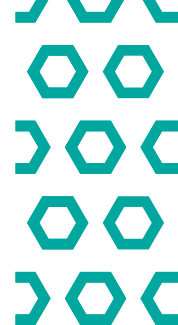


prostheses and orthotics that they acquire through either the second-hand trade or donations from deceased users, or through donations from NGOs or religious organisations. Donations, primarily from the LDS, comprise the vast majority of APs that the centres provide, which they track in a database. Though services at the centre are free of charge, cost-recovery fees are sometimes charged to increase the centres' revenue stream. Finally, patients must be referred from hospitals to be seen at one of the centres, but most visitors to the centres hear about them through word-of-mouth. The centres are also involved in information-sharing and awareness-raising to increase DP's knowledge about appropriate AT and AT services.

According to some low-income respondents, **public hospitals**, including the 34 Military Hospital, Connaught Hospital and other regional hospitals, are another source of AT, though it is unclear whether hospitals can provide AT or simply refer patients to rehabilitation centres and formal or informal providers and vendors of AT. Respondents report paying for services despite that, according to the Disability Act, public hospitals must offer free medical care to DP. Moreover, due to the limited availability of medical equipment (e.g. x-ray machines) in public hospitals, patients are often forced to go to private hospitals.

## Formal private stakeholders

There are two main formal private sector stakeholders: medical and AT supply shops and private hospitals. The former includes Index Medical and Laboratory Equipment in Freetown, the only **medical supply shop** in Sierra Leone, which offers new wheelchairs, walkers, and crutches as well as paid, on-demand training in AT use from a retired physiotherapist from one of the public hospitals. The shop's prices—wheelchairs cost between SLL 3-5 million (USD 308-512) and crutches are SLL 500,000 (USD 51)—are beyond the reach of low-income users, which is why the shop's main customers are higher-income individuals and NGOs purchasing APs for free distribution. On average, the shop sells between 40 and 50 wheelchairs each year, only 10 of which are bought by private individuals. The shop is registered with the Pharmacy Board of Sierra Leone (PBSL), to whom it pays and registers for each item it imports annually in addition to respecting the PBSL requirement to employ



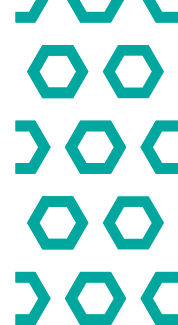
a pharmacist. It is also registered with the Freetown City Council (FCC), the National Revenue Authority (NRA), and the National Social Security Insurance Trust (NaSSIT).

The other AT supply shop is Apex Optics, an **optician** that provides glasses and sunglasses and administers eye exams. The shop hires licensed medical professionals and trains them on the use of its own medical equipment. Here too, low-income users fall outside of the shop's customer base: glasses, including the frames and the lenses, cost at least SLL 400,000 (USD 41) as compared to SLL 20,000-50,000 (USD 2-5) from street traders, and eye tests cost roughly SLL 60,000 (USD 6). During a three-month campaign in 2016, the shop offered free eye care and prescription glasses and sunglasses to people with albinism. Today the shop provides free eye exams for students with albinism, though they do not advertise this service.



Index is the only formal private shop selling APs in Sierra Leone (left).  
Sign showing APs for sale at Index (right). Photos: Julian Walker

Despite the higher cost of **private hospitals** (including the Arab Hospital and the Chinese Hospital), they are nonetheless an important source of AT and AT services for low-income respondents due to the limited supply at public hospitals as well as the better quality of service. Private hospitals sell a range of APs including glasses, hearing aids, walking sticks, crutches, wheelchairs, calipers, and prostheses, and can be found in most of the larger cities around the country. Some private hospitals, including FT Stocco and the Catholic hospital in Masanga, also produce and fit prostheses.



## Civil Society

Civil society actors, which target low-income groups, represent the single biggest source of direct and indirect AT and AT services. The actors vary in formality with regards to both their registration status and their provision of AT, as well as in their scale and scope. **Charities** and **individual philanthropists** distribute a range of AT and, in some cases, provide AT services, including testing and fitting. Composed of both Sierra Leoneans in the country and from the diaspora as well as non-Sierra Leoneans, this support takes the form of campaigns, one-off interventions, financial and non-financial contributions, as well as donations to specific individuals, and may be offered directly or via government actors, NGOs, DPOs, churches, and more. The quality of AT and AT services offered varies and is likely to depend on the financial resources available. The least 'formal' of this type of distribution involves gifting AT to users by friends, family, and others in their networks, or by benevolent strangers. For donations not channelled through more formal means—for example, through a rehabilitation centre—there is no regulation of quality nor monitoring of numbers.

**Churches** and other **faith-based institutions** represent a similar case, with many low-income respondents describing receiving donations of APs around the holiday season. Some of the religious organisations donating AP or providing AT services include Faith Healing Church, Flaming Bible Church, Faith Assembly, Sanctuary Place, LDS, and the Lonestar Baptist Mobile Eye Clinic. Users may access AT through membership in a particular church or through word-of-mouth from church members. In some cases, churches purchase or channel donated AT as part of their charitable work, whilst others, specifically those that run larger operations, may offer free medical services and provide related APs. In the latter case, users are more likely to receive appropriate, fitted APs. Many larger churches are based in Freetown, but may visit provinces to provide services. Churches distribute wheelchairs, crutches, glasses, white canes, and hearing aids, but the frequency and type of APs they provide is dependent on availability and financing.

Larger faith-based institutions, in particular LDS, play perhaps the largest indirect role in the provision of AT. Through cooperation with the state, LDS provides new wheelchairs, crutches, walkers, white canes, and prostheses, which are then distributed to users through the national and regional

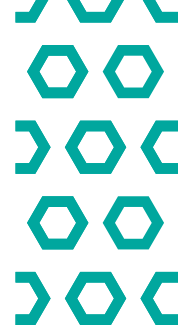


rehabilitation centres. LDS also collaborates with DPOs and other NGOs in the country. Other churches, such as the United Methodist Church (UMC), operate hospitals—in this case Sarola—that offer medical care as well as AT and AT-related services when available. Though mosques also do charitable giving, particularly around Ramadan, they are not involved in AT provision.

**DPOs**, including DP-based workshops, DP-based enterprises, and DP/inclusive schools, are another major player in the provision of AT and AT-related services. SLUDI, established in 1995, is a federation of all DPOs in the country. It serves as a pressure group and advocate for its members on national issues affecting DP; supervises the NCPD, particularly with regards to the NCPD's implementation of the Disability Act; and works with state actors on policy. SLUDI played a crucial role in the establishment of the NCPD and used to receive financial support from the MoSW prior to the NCPD's establishment. Whilst it is not mandated to provide APs, it redirects the donations it receives, including for wheelchairs, PETs, crutches, white canes, and glasses, to its member DPOs for distribution. In addition, recognising the lack of public information relating to proper AT use and provision, SLUDI refers users to government rehabilitation centres and encourages DPOs to do the same.

SLUDI's member organisations are involved in the production, assembly, repair, distribution, and/or fitting of AT, in addition to providing training to users and DPOs on production, maintenance, and repair. These DPOs include:

- **Handicap Action Movement (HAM)**. Though not producers or distributors of AT, HAM trains disabled and non-disabled people in blacksmithing, tin-smithing, welding, tailoring, and electronics. As a result, its mostly disabled membership includes people who can assemble and repair wheelchairs and PETs and produce rubber tips. Providers offer the first two services informally for a small fee and the latter for free. HAM is registered as a DPO with the MoSW and FCC and is a member of SLUDI.
- **Disability Rights Movement (DRIM)**. Based in Bo, DRIM assembles and distributes wheelchairs, crutches, and PETs on behalf of NGOs and other actors; repairs second-hand APs and APs that users bring to them; and produces and distributes wooden crutches and rubber tips. DRIM trains the carpenters and other tradespeople who produce APs and other goods, including agricultural tools.



- **SLAB.** SLAB distributes white canes provided by NGOs such as Sightsavers and state actors such as SLUDI and the MoSW.
- **St Joseph's School for the Hearing Impaired.** Based in Makeni, St Joseph's hosts an audiology specialist and provides hearing tests as well as fitting, programming, and distribution of hearing aids. Run by the Catholic mission, it is one of the MoE's recognised schools for the hearing impaired and provides free support to other such schools throughout the country. The APs it distributes are mostly donations from NGOs, charities, and individual philanthropists.
- The United Polio Brothers and Sisters Association (UPBSA) in Freetown; the Welfare Society for the Disabled (WESOFOD) in Kambia; the Polio Handicap Development Association (PHDA) in Waterloo; and the Help Empower Polio Persons Organisation (HEPPO) in Freetown also provide, to varying degrees, AT and AT services, including production, assembly, repair, and distribution of wheelchairs, PETs, crutches, and rubber tips.

### Box 1. MSL

*Founded in 2009 by three Sierra Leoneans trained at the Tanzania Training Centre for Orthopaedic Technology (TATCOT), MSL is the only local producer of mobility devices for DP and serves a crucial role in the provision of AT to low-income users. Based in Bo, its scope extends beyond the country's borders into other West African countries, including Guinea, Togo, Nigeria, and Cameroon. MSL offers a range of services and has, to date, assembled and distributed over 1,500 Rough Rider wheelchairs and 2,200 PETs in partnership with local and international organisations; as well as produced and distributed over 1,000 locally made wheelchairs, over 1,500 white canes, crutches and walkers, and over 100 locally made PETs. MSL also used to produce rubber tips for crutches using imported polypropylene. It employs four disabled and four non-disabled staff and has partnered with the MoSW, MoHS, NCPD, SLUDI, and other local DPOs, as well as with international organisations such as HI, LDS, Mobility Worldwide, and the UNDP. Besides production and assembly, MSL provides spare parts; AT repair; user-assessment and training; capacity-building for DPOs and DP-based workshops on AT production,*



*assembly, and repair; and does advocacy and awareness-raising. Materials are sourced locally and regionally (Guinea, Kenya, and Tanzania) and tools are sometimes imported from the United Kingdom. MSL distributes all of its products for free with support from international organisations, charities, and individual philanthropists. As qualified professionals, the MSL team follows a strict fitting and provision process in which they conduct an initial screening and assessment, both of the physical condition of the potential user (their physical impairment, strength level, etc.), as well as of their lifestyle, to ascertain the type of terrain they normally move on and the activities they do. This determines which AP(s) they receive, including the size, style (ex. three or four wheels), and type (ex. PET, wheelchair, or crutch). MSL has limited work and storage space and struggles to import material for production and assembly as well as to transport assembled APs for distribution around the country. Despite gaining significant recognition for their work, MSL's financial constraints mean that it continues to rely on government support. It nonetheless represents an excellent step towards increased self-sufficiency in Sierra Leone.*

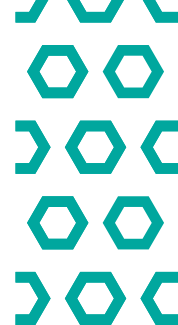


AT produced by MSL: PETs (left); replacement rubber tip for crutches (right). Photos: Nada Sallam



**NGOs**, which range in scale, scope, and types of activities undertaken, are the last major civil society group involved in the provision of AT and AT services. In most cases, NGOs are registered formally and, though not locally mandated, focus specifically on issues relating to DP or medical issues more broadly. As such, they employ people with the relevant skills and qualifications, making the AT and services they provide often reliable and of a high standard despite limited (if any) state quality control. Some NGOs partner with local DPOs to provide AT and AT services, as is the case with Whirlwind Wheelchair International, the Abilis Foundation, and Mobility Worldwide who work with MSL. Other NGOs run in-country operations working directly with low-income users and alongside state and non-state actors. A few of these organisations include:

- *Sightsavers*: Though no longer as actively involved in AT provision, Sightsavers has served as the primary provider of APs for visually impaired people, namely recorders, typing machines, cassettes, Parkins-Brailer (braille machines), stilos, writing frames, white canes, and glasses; in addition to hearing aids, crutches, and prostheses. They also play a role in supporting AT services and service providers through training staff, providing materials and medical equipment, building and managing clinics (including the eye clinics at various public hospitals in the past), and covering the cost of medical tests. Not all of the services they offer are free, but the organisation nevertheless fills a gap in the provision of accessible and affordable AT to low-income groups.
- *HI*: HI has long played a significant role in the provision of AT and AT services, establishing and managing state rehabilitation centres before the centres were turned over to the MoHS in the late 2000s. Because of this history, low-income respondents often incorrectly believe that HI remains the country's major source of AT. Instead, HI's model has shifted and it no longer provides AT and AT services at the same scale. In the past, it provided fitting, training, distribution and repair of prostheses, calipers, crutches, walking sticks, and wheelchairs, in addition to rehabilitation and physiotherapy. Its current AT work is through a UK FCDO funded project which focuses on school children, funding and linking service providers (e.g. opticians) with schools to conduct tests and provide necessary APs. The organisation hopes that the MoE will eventually assume this role and provide all disabled children with the APs they need to enable their access to education. There is



some scepticism as to whether this handover is feasible, however, because of the prohibitive price of APs like hearing aids and prostheses.

- *Mercy Ships*. Despite last docking at the port of Freetown in 2011, low-income respondents consistently mention Mercy Ships as a key source of AT and AT services. In the past, Mercy Ships provided mostly free access to crutches, prostheses, calipers, and glasses, as well as testing, fitting, training, surgery, rehabilitation, and physiotherapy. In 2000, they established a land-based centre in Waterloo to provide “holistic physical rehabilitation, healthcare, personal development and community development services.”<sup>20</sup> According to some sources, however, there was limited demand and the centre soon closed. Mercy Ships recently signed an Accord de Siège and Protocol Agreement with the government of Sierra Leone establishing a “country engagement plan for 2019-2023,” signifying its plan to return in the near future.<sup>21</sup>

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20. <https://reliefweb.int/report/sierra-leone/mobility-matters-polio-disabled-sierra-leone>

21. <https://www.mercyships.org/blog/mercy-ships-signs-agreements-to-return-to-sierra-leone-in-future/>



## Box 2. Enable the Children (ETC) (World Hope International)

*ETC provides physiotherapy, occupational therapy, and other support services to disabled children, many of whom have cerebral palsy, Down syndrome, muscular dystrophy, and other orthopaedic challenges.<sup>22</sup> As such, ETC offers a variety of APs and AT-related services to their patients, in addition to producing and selling APs to DPOs and NGOs. ETC currently produces two main types of APs: splints (wrist, upper limb, and lower limb) and furniture (corner seats, tilted corner seats, standing frames, commodes, tables, and walkers). ETC designs the splints and then a tailor and a carpenter manufacture them using training and material they receive through the organisation. ETC then fits and distributes the splints for free to the children with whom they work and produces others on request for NGOs and DPOs at SLL 35,000 (USD 4) for wrist splints, SLL 45,000 (USD 5) for elbow splints, and SLL 90,000 (USD 9) for leg splints. Prior to starting local production in 2009, ETC relied on donations from friends of staff, which proved both impractical and unreliable. Moreover, products were often not durable, padded, or fitted for their users. With regards to furniture, ETC produces a range of paediatric furniture designed specifically for*



APs produced by ETC: Secure seat (left); walking frame/desk (centre); arm brace (right). Photos: Nada Sallam

22. <https://www.worldhope.org/our-work/health-and-nutrition/enable-the-children/>



*disabled children. The designs are based in part on a book by David Werner entitled Disabled village children: A guide for community health workers, rehabilitation workers, and families,<sup>23</sup> but have been improved through experience and user/carer feedback. For the tables and chairs, which began production in 2007, an ETC-trained carpenter manages the woodwork, after which, where applicable, ETC fits the foam, covering, and straps. The same applies to the standing frames and walkers which began production in 2016. Here too, products are distributed for free to ETC's patients and sold to others at SLL 190,000 (USD 19) for a corner seat and table, SLL 200,000 (USD 21) for commodes, and SLL 250,000 (USD 26) for tilted chairs, standing frames, and walkers. In addition to what ETC produces, the organisation also obtains and distributes other AT, including paediatric crutches, stability boots, wheelchairs, and, less frequently, prostheses and calipers. They receive some of these APs as individual and others as part of projects with NGOs and DPOs. Because imported products are often difficult to adjust and repair, particularly higher-tech products, ETC prefers to provide locally-produced APs where possible. As trained professionals, ETC staff offer training to children and their carers on the proper use of AT and monitoring users' development and progress. Where necessary, ETC replaces APs that are no longer needed or no longer fit and redistributes some of them to other patients. By combining professional knowledge, experience, and improvisation, ETC produces crucial AT for disabled children and invaluable and holistic support to them and their carers.*

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23. [https://www.goodreads.com/book/show/651812.Disabled\\_Village\\_Children](https://www.goodreads.com/book/show/651812.Disabled_Village_Children)



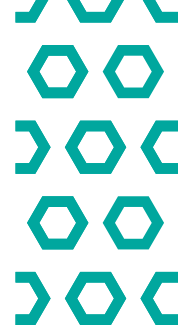
## Semi-formal private stakeholders

A large portion of informal private stakeholders linked to AT are formally registered businesses but informal or unofficial distributors and/or producers of AT because they lack the certifications required by formal suppliers such as Apex or Index. This includes second-hand shops as well as carpenters, welders, car mechanics, and other tradespeople.

**Second-hand (or 'junks') shops** primarily sell mobility devices, including wheelchairs, crutches, walking sticks, and walkers. The biggest concentration of second-hand shops is in Freetown's central commercial district around Kissy Road. Second-hand shop owners acquire APs in a variety of ways:

- Going to the port or other places like Cline Town where shipping containers of second-hand goods from abroad are offloaded and purchasing goods they plan to resell;
- Buying goods directly off of ju-men, or second-hand traders, who visit the containers but have no premises from which to sell;
- Buying goods from other second-hand shops which may or may not obtain their goods from containers; and
- Receiving direct shipments from friends or family living abroad.

Though most, if not all, of the goods in the containers are second-hand, there is no way to determine whether they were intended as donations or for resale. Many second-hand shops repair and assemble imported second-hand APs before reselling them, but users do not seek AP repairs at second-hand shops. The APs at these shops range in price, with wheelchairs costing between SLL 200,000–500,000 (USD 20–50); crutches for SLL 100,000–200,000 (USD 10–20); and walkers for around SLL 300,000 (USD 30). These price points are largely unaffordable for low-income users, though not as expensive as APs sold at the private medical supply shop. Another issue for users relying on second-hand shops is that none of these shops specialise in sourcing or selling APs, leaving users, DPOs, and NGOs to search the Kissy Road area for specific APs or APs to fit specific requirements, such as size, and spread the word through their networks. Many respondents, including DPOs and the National Rehabilitation Centre, describe going to second-hand



shops even when access to free APs is limited, the need is urgent, and money is available. NGOs also visit second-hand shops but only purchase the APs that meet their minimum quality standards. Whilst all the second-hand shops we spoke to were registered with the FCC and NRA, they did not interact with any government agencies that regulate medical supplies. Moreover, though one shop owner suggested that the state's Consumer Protection Unit (CPU) was responsible for regulating the quality of their products, no one mentioned having been visited by them.



The second-hand trade district around Kissy Road (left). Second-hand APs for sale in Kissy Road (right). Photos: Julian Walker/ Nada Sallam

The second group, namely **carpenters**, **welders**, and **car mechanics**, manufacture crutches, walking sticks, and rubber tips for DP in addition to offering repair services. In most instances, they manufacture AP on commission, with none exclusively offering APs. Some tradespeople received training from DPOs whilst others follow customers' instructions. Tradespeople who are themselves disabled may be aware of basic quality standards and make design adjustments to improve comfort and durability based on their own experience, but others improvise or assume the user will make specific

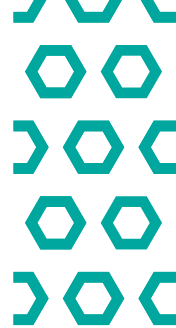


requests. Crutches and walking sticks are most commonly made by carpenters using wood, while rubber tips are made using old tires in car repair shops. Welders and mechanics may repair crutches and wheelchairs that lose bolts or require adaptations to meet the user's physical condition or lifestyle. Whilst many will do these repairs for free or for a nominal fee to support low-income users, they charge between SLL 10,000-50,000 (USD 1-5) to manufacture walking sticks and crutches.

**Street traders** represent the third key stakeholder in the informal private sector. Unlike the other two, street traders are informal in terms of their registration status and their distribution of APs. The main APs they provide are glasses and sunglasses, which they sell for SLL 20,000-50,000 (USD 2-5). Many glasses are for reading, often referred to as 'Chinese glasses,' as they are shipped in bulk and sold by tradespeople and in pharmacies and other small shops. As street traders sell glasses with prescription stickers on them, many users view them as a useful and more affordable alternative to optician shops.

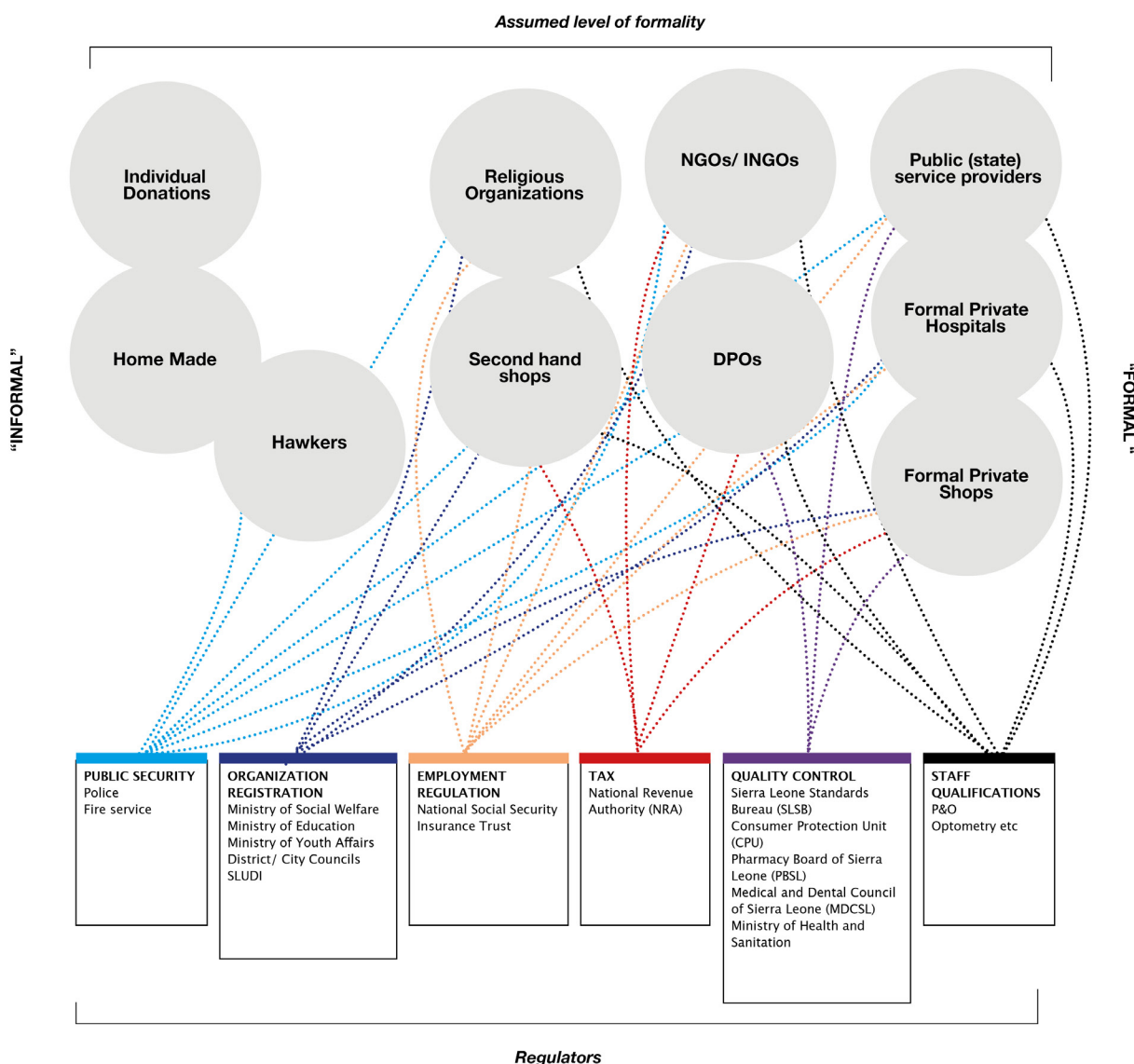
## Users

Individual **AT users** who produce, assemble, adapt, maintain, and/or repair their own APs represent the last key stakeholder in the AT sector. Some users develop their own APs (specifically in the case of crutches and walking sticks), whilst others assemble, adapt, maintain, and repair what they have accessed through other sources. Users may learn from others, both formally (e.g. through DPO trainings) and informally (e.g. speaking to other AT users); but many rely on experience and accumulated knowledge with regards to both APs and their own specific disabilities and needs. Users may also train others and/or offer support (e.g. repairing others' APs) and advice (e.g. providing tips on how to adapt APs to improve their functionality). Finally, we were unable to find any small-scale AP businesses run by AT users, but, given the limited availability of APs in Sierra Leone (particularly in rural areas) and the size of the informal enterprise sector, it is likely that some users are involved in basic production and/or maintenance, repair, etc.



## The range of informalities across AT providers

There is no clear distinction between formal (regulated and qualified) providers and informal (unregulated and untrained) categories of providers. Rather, as Figure 8 shows, there is a mosaic of regulations that may or may not apply across providers. Critically, only some of these regulations are related to the quality and safety of AT.



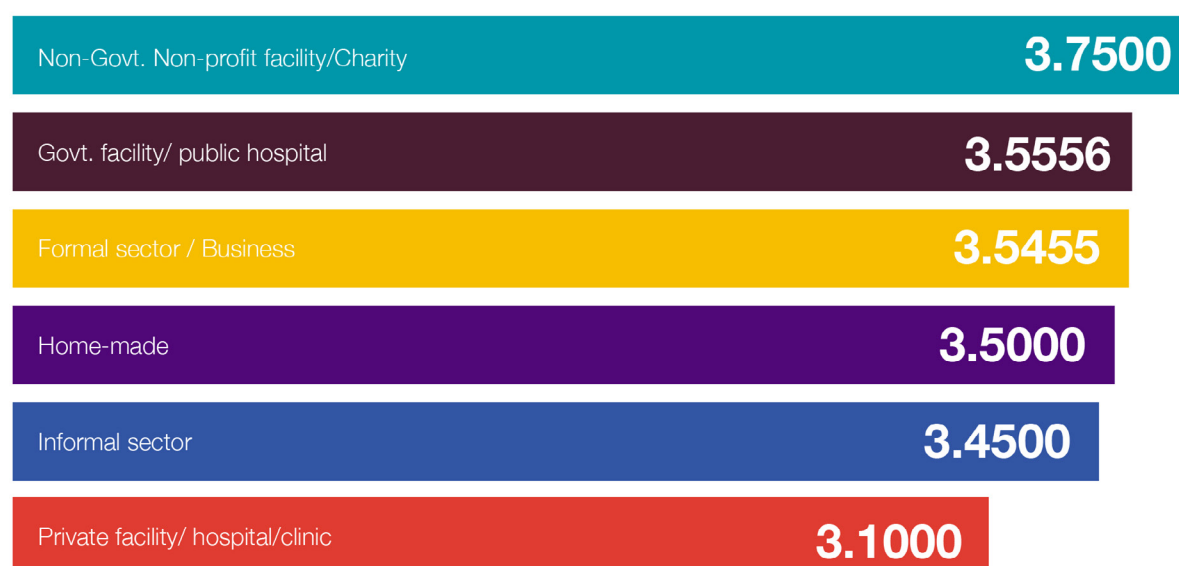
**Figure 8:** A typology of formal and informal AT providers and the regulatory relations in place



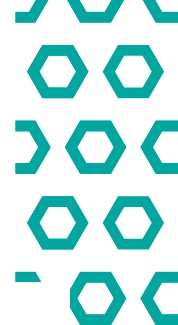
## User perspectives on informal AT and AT service provision

Given the wide reach and relative popularity of informal AT and AT service provision, the following section explores their associated advantages and disadvantages to better understand why users opt for informal providers. Because informal sources of AT vary as do the quality of products and services offered, the advantages associated with informal provision must be weighed against the potential risks emerging from unregulated provision, such as low-quality APs exacerbating users' existing conditions.

We explored AT users' satisfaction with both AT and AT services from more formal and more informal providers during interviews and FGDs with AT users in Thompson Bay and Dwozark. We also investigated users' satisfaction with APs and AT services from different provider types (see Figures 5 and 6 below).



**Figure 9:** Satisfaction with AP by provider type in Thompson Bay and Dwozark (rATA Survey). Average (mean) satisfaction with AP from providers ranging from 1 (Very dissatisfied) to 5 (Very satisfied)

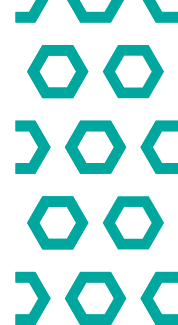


**Figure 10:** Satisfaction with AP service by provider type in Thompson Bay and Dwozark (rATA Survey). Average (mean) satisfaction with the service given by AT ranging from 1 (Very dissatisfied) to 5 (Very satisfied)

As illustrated in Figures 9 and 10, there is only a marginal difference in average satisfaction with APs and AP services from formal and informal providers, indicating a balanced evaluation of the advantages and disadvantages of informal AT providers.

## Advantages

- **Cost:** Informal providers consistently offer AT and AT services—including both new and used goods—at a lower price point than formal private businesses whose high costs are beyond the reach of low-income users. Low-income users also access free APs and associated services far more frequently through civil society actors and other informal means due to the financial constraints that formal actors face which limit what they can offer, as with the state's rehabilitation centres.
- **Accessibility and availability:** AT and AT services are more readily available through informal providers, which users can find around the country (e.g. second-hand shops in Bo and DP-based workshops in Makeni), and repairs are more easily, quickly, and cheaply done informally, perhaps due to the limited incentives and conditions for formal networks of AT provision. The



high price of AT sold through formal private businesses keeps demand low and limits incentives to expand or create new businesses. Index remains the country's only medical supply shop with no plans for expansion outside of Freetown. Thus, though increased competition could drive down prices, little is done to enable it. On the other hand, though formal state actors generally provide AT for free, their own financial constraints limit their supply and geographical reach.

- *Adaptability and ease of repair:* APs accessed through informal providers are often more easily customised and repaired, especially self-made and commissioned APs. In contrast, the process of maintaining and repairing imported products can be onerous, particularly when spare parts are required, plus customisation is more difficult. Thus, where possible, acquiring APs from informal sources allows users to shape products according to their needs and physical conditions. Moreover, locally produced products—walking sticks, crutches, and rubber tips— are often more durable than imported ones.

## Disadvantages

- *Variety:* Perhaps the biggest shortcoming of the informal market is the variety of APs available. In the case of many mobility devices such as walking sticks, crutches, and PETs, informal production, provision, and repair are relatively easy and affordable. APs that are more complex to produce, prescribe, and fit, however, such as prostheses and hearing aids, require more advanced technologies, are more expensive, and cannot and should not be used second-hand. As such, they are much less likely to be available through informal providers.
- *Fit and quality:* When APs are donated, second-hand, or cheaply made, their poor quality, durability, performance, and fit can aggravate users' injuries and exacerbate pain, worsening existing conditions. Similarly, older products may not withstand the local terrain or be appropriate for people's lifestyles. In addition, since many informal providers are not qualified professionals, users' may receive APs that are not suited to their needs as well as insufficient training on their use and maintenance.



## AT users: Case studies

### Box 3: Mr S: From AT user to AP producer

*Mr S became visually impaired in 1998 after being hit in the eye by a bullet fragment during the civil war. He was sent to Connaught Hospital where he received stitches, but the wound became infected. In 2001, Mr S learned about Mercy Ships from his brother who was working as a driver for one of the organisation's doctors. Mercy Ships operated on his eye and provided him with eyedrops and clear, non-prescription, protective glasses, all at no cost. Though the glasses were of good quality, Mr S explains, he eventually needed to replace them and, given his limited financial resources, he purchased glasses from a street trader at SLL 25,000–30,000 (USD 2.5–3), which he has since needed to replace many times. He now no longer buys glasses at all and is largely unable to afford medication, which he has been unable to obtain for free from Connaught Hospital, despite his right to free healthcare as a disabled person, of which he is aware. As a young man, Mr S trained as a carpenter alongside two other DP and now runs his own carpentry shop, as do his co-trainees. Whilst he was still an apprentice, he watched his boss making walking sticks, primarily for the elderly, and today he makes sticks on commission, either for free or for a fee of SLL 10,000 SLL (USD1). Demand is low, however, so he only produces about five sticks at his shop each year.*

### Box 4: Mr B: Adapting APs for sports

*During the civil war, Mr B was deployed to Kenema as a soldier. In 1994, he was hit by an anti-personnel mine and sent to the 34 Military Hospital where he remained for two years. Following the amputation of his left leg, Mr B received a wheelchair at the hospital and trained to use elbow crutches whilst undergoing rehabilitation. He received support from HI, which ran the rehabilitation centre in Aberdeen (now the national rehabilitation centre), where he had his prosthetic leg made. Despite being fitted and trained on its use by HI, he developed blisters on the stump and found moving around easier without the prosthesis and went back to using crutches. Since then, Mr B has gone through several pairs of crutches, some that he was given and*

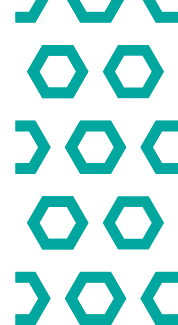


*others that he bought from second-hand shops and people he knows after negotiating the price down to SLL 50,000 (USD 5) per pair. Mr B is the captain of the Sierra Leone amputee football team, which was founded in 1996 and registered as a DPO. In order to play, he adapts his crutches, stitching the elbow grip shut with metal wiring so that the crutches do not fall off when he raises his arms to jump or kick. He also regularly replaces the rubber tips of his crutches—which, he explains, are the first to deteriorate—as well as the crutches' metal feet. He purchases replacement tips made of rubber from car tires at garages and workshops, which he describes as significantly more durable than the originals. As the captain of the football team, Mr B has a wide network through which he is able to access APs, but because he relies on his limited veteran's pension as income, which is SLL 600,000 (USD 60) per month, he cannot afford more expensive APs or AT services and he struggles with limited state support for DP.*



Mr B, captain of the Sierra Leone amputee football team, with crutches that he adapted for playing football and old crutches that he repaired himself.

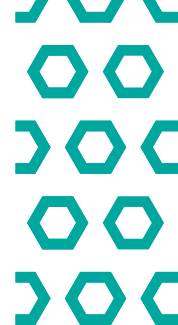
Photo: Angus Stewart



### **Box 5: Ms E and HEPP0: A community of AT users**

*Ms E is the Chairwoman of HEPP0, a DPO registered with the FCC and a member of SLUDI that was established in 1995. HEPP0 has between 70 and 80 members who live on a plot of land owned by the Ministry of Works, Housing, and Infrastructural Development (MoW), which they found and began squatting on in 1993 when the site was a vacant dumpsite. The MoW repeatedly attempted to evict the residents, but HEPP0 successfully resisted eviction with the support of human rights organisations, including the Human Rights Commission, and NGOs such as One Family People. Additional members would like to move onto the site, but overcrowding and poor living conditions make this difficult, so many live on the street and continue to depend on begging for their livelihood.*

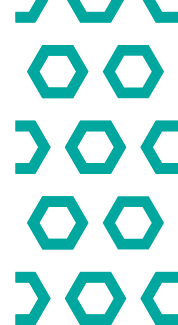
*In the past, HEPP0 members accessed APs (primarily wheelchairs and PETs) through NGOs such as Mercy Ships and HI), churches, and individual philanthropists. Since the national rehabilitation centres came under the control of the state around a decade ago, however, residents have had to purchase most AT, a measure Ms E believes is the result of limited supply and an effort to reduce the likelihood of donated wheelchairs being resold. Ms E purchased her wheelchair from the state's national rehabilitation centre in Aberdeen for SLL 300,000 (USD 30). The centre registered the wheelchair in her name using the wheelchair's serial number in order to more easily track it down in case of theft. Though Ms E made the purchase in late 2018, the wheelchair is much older; Ms E notes that the wooden seat is nearly broken. When she and other HEPP0 members need AT repairs, they go to the carpentry shops next-door, which would charge SLL 30,000 (USD 3) to repair the her wheelchair seat, or nearby car repair workshops which offer rubber tips for free or a fee of SLL 5,000 (USD 0.5). Though rehabilitation centres do free repairs, Ms E chooses to go to the nearby carpentry and car repair shops because getting to Aberdeen would require paying someone to push her all the way there, which would be too costly. Other HEPP0 members purchase crutches from second-hand shops when they have money available, but they rarely buy wheelchairs which are both too expensive and not appropriate for their condition since many are hospital wheelchairs. HEPP0 still receives inconsistent donations of AT, particularly PETs, which are easier*



*to repair. In addition, many members have learnt how to maintain and repair their own APs and support those who are unable to do the same. When new wheelchairs are donated, for example, members often come with tools such as spanners which they keep for future maintenance or repair. When funds are available, spare parts may be sourced from motorcycle dealers, particularly for wheels.*



Ms E, the Chairwoman of HEPPD  
Photo: Angus Stewart



## 7. Policy and finance

### Policy

Though disability is increasingly a political priority in Sierra Leone—demonstrated, for example, in the Transform Freetown Mayoral Strategy—few policies refer directly to AT. Moreover, implementation is limited and provision is irregular, so there is a significant gap between policy and the law on one hand and practice on the other. The country also lacks AT procurement protocols, leaving civil society to serve as the main, unregulated provider of AT and AT services. Similarly, although the MoHS is mandated with developing standards for APs and procurement, there are no official or enforced minimum standards or quality controls with regards to provision, production, or procurement.

The policies relating to DP have limited provisions pertaining to AT and AT services:

- The 1991 Constitution of Sierra Leone references the rights of DP, but makes no mention of AT or AT services. Instead, it states that the government “shall direct its policy towards ensuring that— the care and welfare of the aged, young and disabled shall be actively promoted and safeguarded”<sup>24</sup> and “there are equal rights and adequate educational opportunities for all citizens at all levels by— safeguarding the rights of vulnerable groups, such as children, women and the disabled in security educational facilities.”<sup>25</sup>
- The 2001 NaSSIT offers social security to everyone with formal employment, including DP. Here too, however, there are no provisions pertaining to AT or AT services and low-income people’s limited employment in the formal economy excludes most of the population.
- The 2004 Education Act guarantees access to free primary education for all children, including those with disabilities, although it does not make reference to interventions to ensure access to AT to support inclusive education.

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24. Section 8(3) f. of 1991 Constitution

25. Section 9(1) b. of 1991 Constitution



- In 2010, the government ratified the Convention on the Rights of Persons with Disability (CRPD), but chose not to ratify the optional provisions. Though the CRPD does not set out specific obligations for states to provide AT to DP, it does require states to facilitate the development of suitable APs and to facilitate access to and information about AT for DP.<sup>26</sup> The government is working on its first country report since ratifying the convention, which includes a chapter on rehabilitation. DPOs and other actors are hopeful that the report will address the state of AT and AT services in the country. One Family People is preparing a parallel civil society shadow report with a specific focus on the implementation of AT policy and law.
- In 2011, the government enacted the Persons with Disability Act, the most comprehensive policy in the country pertaining to disability issues. It established the NCPD in 2012 and disability issue units across the ministries, in addition to provisioning the issuance of “Permanent Disability Certificates to persons with disability to make them eligible to all the rights and privileges provided for persons with disability under [the] Act,”<sup>27</sup> though this has yet to be implemented. The Act also outlines the rights of all DP to “free medical services in public health institutions,” which was not guaranteed under the 2010 Free Healthcare Initiative.<sup>28</sup> The Act does not explicitly mention access to AT or AT services, however, and DP we interviewed have not always received free healthcare at hospitals. Participants also noted that, whilst they are aware that they have a right to free healthcare, they hesitate to request it for fear of irritating hospital staff and consequently receiving poor service or being refused service.

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26. Through “Article 4 - General Obligations”, states commit to: “(g) undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost”; and “(h) provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities”. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html>

27. Disability Act 2011 Section 7(1) a.

28. This was restricted to pregnant and lactating mothers and children under five.



- The 2017 Social Health Insurance Act “aims to provide free OPD (outpatient) treatment for identified ailments. However, the scheme is still on the paper and implementation is yet to begin. Nevertheless, the scheme has limited benefits for physically disabled people as there is no provision for AT services and devices”.<sup>29</sup>
- In 2019, the MoHS began developing the National Assistive Technology Programme Guidelines “with strong support [and] political commitment [from] the current government”,<sup>30</sup> but, this too remains in progress.
- The Medium-Term National Development Plan for 2019–2023 contains one AT-related provision, which falls under the strategic objectives to: “ensure the comprehensive review and implementation of policies and laws relating to disability, especially efforts to make public facilities disability friendly; to review and improve incentives for teachers in special needs institutions; to provide free health care for the physically challenged and the aged; and to provide livelihood support to persons living with disability for economic empowerment and self-reliance.”<sup>31</sup> The key policy action is to “provide teaching and learning materials and assistive devices required by PWDs [persons with disability]”.<sup>32</sup>
- At the city level, the Transform Freetown Mayoral Strategy 2019–2022 has a focus on disability including a target to ‘create and improve an enabling environment for persons with disabilities in the areas of work, education and social inclusion’ by 2022. The initiatives to support this goal focus primarily on training, however, and there are no explicit activities or commitments related to AT.

In terms of the translation of policy into procedures and regulations, there are several areas relevant to the formality of AT providers.

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29. Clinton Health Access Initiative, (2019) Assistive Technology Country Capacity Assessment Sierra Leone, CHAI, Freetown, p.10

30. Clinton Health Access Initiative, (2019) Assistive Technology Country Capacity Assessment Sierra Leone, CHAI, Freetown, p.10

31. Medium-Term National Development Plan 2019–2023, Section 5.3: Empowering persons with disabilities (p.142–143)

32. Medium-Term National Development Plan 2019–2023, Section 5.3: Empowering persons with disabilities (p.143)



With regards to regulating quality control, formal commercial businesses must register with and get approval from the government to sell their products. Index went through this process with PBSL, whilst Apex Optics applied with the Medical and Dental Council of Sierra Leone (MDCSL). According to Index, there is an office for the Sierra Leone Standards Bureau (SLSB) at the port of entry which requires a certificate of standards for products and makes periodic visits to check the products being sold. They do not look at the APs, however, and limit their inspections to medical chemicals. In addition, to comply with PBSL requirements, Index must employ a part-time pharmacist despite having no need for a pharmacist. The pharmacist's salary is effectively an ongoing payment allowing the store licence to operate rather than a human resource input that could ensure the quality of products or services.

The CPU may also visit second-hand shops but this rarely, if ever, happens. Whilst every second-hand shop that participated in this project was registered with the state, the quality of their products is not regulated. People who import used products to resell to or through second-hand shops pay import duties, but are likewise not bound by quality regulations. Finally, the National Rehabilitation Centre keeps a record of the registration numbers of wheelchairs that they issue to allow the police to do spot checks of second-hand wheelchairs sold in shops in areas such as Kissy Road to prevent the sale of used or stolen wheelchairs.

The amount of red tape and the cost to register formal commercial businesses pushes some AT providers into the informal economy (for example, individuals who sell new AT out of their homes), but little is done to ensure that commercial providers, including formally registered ones, are providing quality products.

Civil society actors, including NGOs, charities, churches, and individual philanthropists, are likewise not monitored when they provide and produce AT despite being legally registered entities. As a result, the government is not able to track the distribution or quality of APs or associated services.



## Finance

Because finance is a significant challenge for government programmes and policies, whilst there may be provisions for the distribution or disbursement of funds for a particular purpose, the funding to support these initiatives is often not available. Nevertheless, there are official financial commitments linked to the provision of APs and AT services:

- The 2011 Disability Act outlines financial measures ranging from the establishment of a National Development Fund for Persons with Disability to the introduction of relief packages and incentives.
  - › Part VI of the Act outlines the first of these measures within the NCPD which is intended to be used to: *“a) contribute to the expenses, including capital expenses, of organisations of or for persons with disabilities; (b) contribute to the expenses, including capital expenses, of institutions that train carers of persons with disability; (c) contribute to the capital expenses of projects undertaken by the Government for the benefit of persons with disability; and (d) provide or contribute to the cost of assistive devices and services.”*<sup>33</sup> Because the fund is not sufficiently resourced, however, it has yet to constitute a significant source of financing for AT or AT service provision.
  - › Part VII of the Act pertains to relief and incentives and states that: *“Materials, articles, equipment and motor vehicles that are modified or designed for the use of persons with disability shall be exempt from import duty, goods and services tax, demurrage charges, port charges and any other levy which would in any way increase their cost to the disadvantage of persons with disability”*<sup>34</sup> and that *“all goods, items, implements or equipment donated to organizations of or for persons with disability shall be exempt from import duties.”*<sup>35</sup> According to both the MoSW and the NCPD, however, this clause pertains only to entities providing APs for free and thus does not extend to commercial providers. DPOs further note that the process is difficult and lacks transparency. One NGO describes having shipments held at the port

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33. Disability Act (2011) Section 31(4)

34. Disability Act (2011) Section 33(1)

35. Disability Act (2011) Section 33(2)



for several weeks, forcing a delay in collection and allowing the port authority to request extra demurrage charges of up to SLL 5 million (around USD 500). As a result, some DPOs import APs in smaller quantities shipped by delivery companies in boxes rather than containers to avoid the bureaucracy of importing at scale. This is not possible for people importing larger APs such as wheelchairs and PETs.

- › The Act also provisions tax deductions, stating that *“Any donation, bequest, subsidy or financial assistance which may be made to the Commission or Government agency or organisation involved in the rehabilitation of persons with disability shall be allowed as a deduction from the donor’s gross income for the purpose of computing taxable income.”*<sup>36</sup> The act also provides investment incentives: *“The Minister responsible for finance or other appropriate authority shall endeavour to provide, subject to any other relevant enactment, incentives to local manufacturers of technical aids and appliances used by persons with disability in accordance with the investment incentives policy approved by Cabinet.”*<sup>37</sup> Nonetheless, none of the local producers who participated in this project have received such incentives.
- The Ministry of Finance (MoF) allocates a ring-fenced amount of funding to the MoSW to disburse as grants to select welfare institutions each quarter. The MoSW receives requests from various institutions, including DPOs, which it then screens and assesses. Applicants must submit detailed proposals outlining exactly what the money will be used for by line item rather than as an open-ended request. Upon approval, the MoSW prepares a list of proposed beneficiaries and sends it to the MoF, which then cross-checks each institution’s legal status and remits the money to the institutions directly. Institutions are judged in part on their capacity to use the money effectively and funding can be progressively increased over time based on demonstrated impact. Though the focus is not specifically on AT, by allowing the MoSW to fund DPOs working on critical issues, the ministry can support the manufacturing, repair, and purchase of AT. Thus far, however, this has not constituted a significant source of AT financing.

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36. Disability Act (2011) Section 34(1)

37. Disability Act (2011) Section 34(2)



- According to government sources, the MoHS is allocating funds to cover the cost of purchasing imported AT rather than local production. It is unclear what will come of this.

**ODA** (Official development assistance) represents an important source of funding for AT, though this is largely in the form of mainstreaming AT provision into education projects, i.e. providing APs to students to ensure inclusion in education, rather than projects targeting AT users or disability.

● Yes   
 ● No   
 ● No response

#### Private facility / hospital / clinic



#### Non-Govt. Non-profit facility / Charity



#### Informal sector



#### Home-made



#### Govt. facility/ public hospital



#### Formal sector / Business

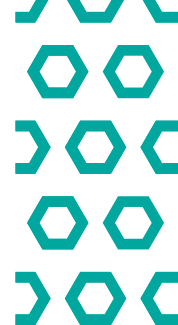


**Figure 11:** Whether AT users had to pay for their AP by provider type in Thompson Bay and Dwozark (rATA Survey)



For example, the FCDO-funded GLADI project seeks to make education inclusive with reference to gender and disability. The project, supported by HI, involves providing APs and training teachers to identify students who have different learning needs in order to provide them with three core APs (glasses, crutches, and hearing aids) as necessary. The intent is that the MoE will take over this process and its budget, including providing access to free APs, as part of the national commitment to Free Quality Education.

Despite the importance of ODA, our fieldwork suggests that the main source of AT financing for low-income people is **charitable donations** from NGOs, DPOs, religious bodies, and private individuals, or **self-financing**. Our survey shows, for example, that 78% of spectacle users paid for their glasses. Self-financing also includes users who access APs and associated services from public facilities since government hospitals and national rehabilitation centres charge for equipment and service.



## 8. Knowledge and skills

### Formal training and qualifications for AT and AT service provision

There is a severe shortage of qualified rehabilitation professionals in Sierra Leone with most having trained in universities abroad. Many of the other qualified professionals in the country are non-nationals and often working for NGOs and charities.

The Tonkolili District College of Health Sciences is the only educational institute to offer a BSc in Physiotherapy and another institute offers a degree and diploma course in Prosthetics and Orthotics.<sup>38</sup> Both institutes enrol a small number of students each year and face significant financial limitations. Likewise, finances pose a challenge to ambitions to train more people through the government's rehabilitation centres to ensure that there are enough professionals to take over from the current generation.

Organisations such as MSL, whose founders were educated abroad, offer basic training on assembly and repair of wheelchairs, PETs, and other mobility devices, as well as on early identification of DP. Their work is limited in scope, however, and relies primarily on securing sufficient project funding. Other DPOs, including DRIM and WESOFOD, also offer training to disabled and non-disabled people on AP assembly and repair, and on manufacturing and producing crutches, walking sticks, and rubber tips. ETC trains carpenters and tailors to produce splints and specially designed chairs and tables for disabled children. To ensure that the APs are not mass-produced at poor quality, few people have been trained. St Joseph's School for the Hearing Impaired hosts one of the country's few audiologists and trained staff at the National School for the Deaf in Freetown to conduct hearing tests. Staff have not yet been trained on programming and fitting hearing aids, however, so they continue to rely on St Joseph's for support.

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38. Clinton Health Access Initiative, (2019) Assistive Technology Country Capacity Assessment Sierra Leone, CHAI, Freetown, p12



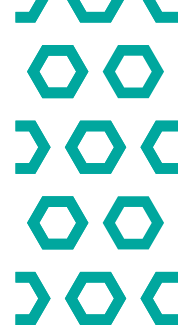
## AT users' access to information

To date, there are no established minimum standards or quality controls for AT production or provision, leaving users dependent on providers for testing, fitting, and essential information about maintenance and repair. When users access AT through formal public providers such as rehabilitation centres and hospitals, they benefit from the knowledge and professionalism of trained staff and, as such, are more likely to receive training and appropriate and fitted APs. Private formal providers, such as the medical supply shop Index and opticians, may offer tests, fitting, and training for users from qualified staff for a fee.

Many of the DPOs that produce or distribute ATs work to ensure that users receive appropriate and properly fitted AT, particularly when staff have specialised training, as in the case of MSL. DPOs also play a role in educating DP and AT users about the rights guaranteed to them in the CRPD and the 2011 National Persons with Disabilities Act. As a result, many of the DP who participated in our study are aware of both their rights (such as access to free healthcare) and the denial and violation of those rights .

Low-income AT users also rely heavily on **informal information** networks. AT users living and working with other users—in the HEPPPO community for example—obtain information from each other. This information may include when donations of APs are available (e.g. from churches or when the Mercy Ship is visiting), when specific APs are available in the second-hand markets of Kissy Road, and how to repair and modify APs or access AT services from informal providers. Furthermore, while some DPOs employ staff with AT-related training and expertise, staff may also gain knowledge through their own experiences being disabled , and through working with other DP. Private informal providers, such as second-hand shops, have neither the interest nor the capacity to ensure that the APs purchased from their shops are properly fitted or appropriate for users.

Ultimately, users are more likely to rely on their own experience or that of their carers to determine whether something is comfortable, appropriate, and practical. Moreover, users often learn how to maintain or repair their APs through trial and error or by asking others. Even in instances when users access AT through formal sources, repairs are more likely to be done



informally—at home or at carpentry, welding, or car repair shops—as formal sources are often too far away, too costly, or have too slow a turnaround.

### Box 6: Mr C: A self-taught AT user

*Having contracted polio at the age of six, Mr C, a disability rights activist, began walking with the support of a stick, fashioned by his parents out of a branch. He used the stick as a young boy to do everything from walking and dancing to playing football and pole-jumping at school. Mr C had an accident at university and fractured his other leg. He received free crutches at the hospital where he was admitted, but, having spent over a decade using a stick, he found the crutches uncomfortable and restrictive and donated them to another person in need. Today, Mr C continues to use a wooden stick, which he says is more durable and offers better grip than other materials, particularly metal. Nevertheless, over time, the top of his wooden sticks get worn down, becoming smooth and slippery, especially when his hands are wet. Therefore, when he needs a replacement, Mr C goes to a carpenter who makes him a stick at the height he wants, either for free or for a small fee. In the past, his sticks also wore out at the bottom,*



*gradually becoming shorter, so he learnt to add a small, rough, metal plate at the bottom to protect the base and reduce the risk of slipping. Though Mr C enjoys the customisability of his AP, he laments the state's lack of support services, particularly given DP's right to free healthcare.*

Mr C with his homemade stick (left)  
Photo: Nada Sallam



## 9. Conclusions and recommendations

Our study suggests that there is an extremely limited level of AT coverage amongst low-income citizens in Sierra Leone, and that the formal policy commitments to address AT needs are rarely substantiated in practice, largely due to resource constraints and lack of institutional capacity.

In this context, informal providers play a key role in basic AT provisioning. Common informal AT providers include NGOs, DPOs, and religious organisations, which, whilst formal to the extent that most are legally registered as CSOs, are informal as AT providers in that they do not conform to requirements to register with medical bodies or for staff to have specific professional qualifications. Further, informal providers, like formal providers, do not meet minimum AT standards. The other key informal AT providers are the large, usually imported second-hand goods traders as well as tradespeople such as carpenters and motor mechanics who produce and repair basic APs. Again, though most of these businesses are formally registered, they are not regulated as AT providers and lack the formal skills and knowledge for the work they do. The final provider, operating in a complete state of informality but outside the domain of regulation since neither their products nor services pass through AT markets, is AT users.

Reliance on informal providers has a range of disadvantages for those in need of AT. These include providers' inability to produce, prescribe, or fit more complex APs, such as hearing aids or prostheses; poor quality, inconsistent supply, and the lack of associated services such as prescription, fitting, or training on use or maintenance. That said, these providers remain the principal source of AT for most low-income users, and users' relatively high level of satisfaction seems to reflect certain advantages, amongst them that these suppliers are more geographically accessible; more affordable for AT users who cannot access free or donated AT from charities, hospitals, or rehabilitation centres; and that they are more willing or able to customise and fit APs to users' needs.



The context raises challenges for efforts to expand AT access in Sierra Leone:

- How can the benefits of informal AT providers in providing broader and less expensive access to otherwise unserved populations be promoted whilst protecting AT users from unsafe products and services?
- What is a realistic role for under-resourced government agencies in this task?
- How can regulations be introduced to improve quality without pushing providers into the informal market, increasing costs, and reducing accessibility?
- In the absence of state capacity for regulation of informal AT markets and providers, what other forms of non-state regulation could fill this gap?
- How can more formal and informal private AT providers be encouraged to sell AT consistently and affordably?

In response to these challenges, we make the following recommendations, which we group into two areas: **regulation and incentives** and **knowledge and information sharing**.

In terms of **regulation and incentives**, we recommend better understanding and addressing that the currently regulatory regime:

- (a) disincentivises ‘crowding-in’ of formal private providers such as Index, or the transition of informal providers to increasing formality by imposing heavy bureaucratic and regulatory requirements, many of which do not improve the standard of AT for users; and
- (b) lacks the capacity to effectively regulate the quality of APs and AT services that users receive.

To this end, we recommend exploring the following changes to AT regulatory practices:

1. *Extending tax (import duties) benefits specified in the 2011 Disabilities Act to all importers of APs.* The NCPD and MoSW maintain that these incentives only apply to people or organisations importing APs for donation, but both institutions are willing to extend the incentives to

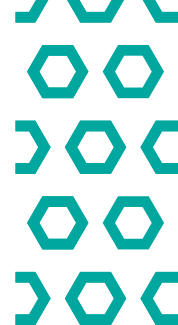


private sellers if that would result in increased affordability, leading importers to reduce the costs of APs they sell rather than increasing their profits. The MoSW is reviewing the Disability Act in 2020 with an eye towards incentivising AT provision in the private sector.

2. *Reviewing and streamlining the regulations applied to formal private AT providers.* Shops such as Index and Apex are ‘over-regulated.’ Index, for example, is required to pay for and periodically update their registrations with the FCC, NASSIT, GST, and NRA in addition to registering with PBSL and hiring a part time pharmacist despite there being no role for this expertise in their business. Besides the costs that this imposes, the registration system does not benefit AT users. If the objective of regulation is to ensure AT without driving up costs for users, the government could consider reducing the financial costs associated with formal registration and reviewing the relevance of specific regulatory requirements for formal businesses that supply APs.
3. *Promoting the ‘social regulation’ of AT providers.* The state has a very limited capacity to regulate informal AT providers. Neither SLSB nor CPU are able to engage at scale with second-hand AP traders around Kissy Road, artisanal AP producers and service providers such as mechanics and carpenters, or religious and social institutions donating APs. We therefore recommend exploring how civil society engagement could supplement the state’s regulation of the sale and production of APs. Precedents exist for promoting the social regulation of highly informal sectors.<sup>39</sup> A first step would be to consult on and agree on the key messages and commitments of a Code of Conduct, which could include, for example, basic fitting services, registration to avoid the resale of stolen or donated APs, or pricing norms. Given SLUDI’s role as a coordinating network for AT users, SLUDI could be a starting point for the initiative.

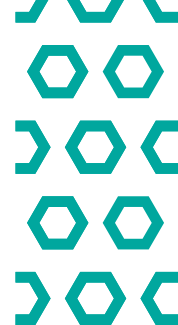
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39. For example, core labour standards were extended to domestic workers in Zambia through popular awareness amongst workers, employers, and the general public using a simplified Code of Conduct and popular communication methods such as radio, plays, and street theatre. See: [https://www.ilo.org/wcmsp5/groups/public/---ed\\_protect/---protrav/---travail/documents/publication/wcms\\_164522.pdf](https://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---travail/documents/publication/wcms_164522.pdf)



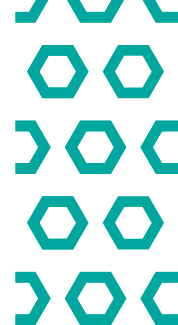
Our recommendations around **knowledge and information sharing** address AP safety and quality for users who access AT without the guidance and support of qualified staff or systemic AT quality control through the application of minimum standards. Information sharing could also enable AT users and DPOs to more efficiently locate and access informally produced and second-hand APs in the context of irregular and intermittent supplies.

4. *Simple AT users' guides.* One resource for AT users could be the development and distribution of a guide to choosing and using APs taking advantage of the expertise of the WHO GATE network and adapting it to the national context in different user countries. Key areas to cover include basic features of commonly used APs which are critical for good functioning and avoiding further health problems (e.g. design flaws that lead to pressure sores), and a list of the APs that should only be prescribed by a qualified professional and should never be adapted or repaired informally (e.g. hearing aids). Given that informal traders and producers of APS are less likely to be concerned with quality issues than users are, we would advise targeting the guide at users and disseminating it through DPOs and user groups, but in the hope that changes in consumer demand would influence providers' behaviour.
5. *Basic 'repair manuals.'* There is also a need for basic information for anyone repairing and adapting APs or commissioning tradespeople to repair or adapt APs. This manual could focus on key APs that are commonly used in order to highlight which APs or components should never be informally repaired as well as guidance on key issues regarding safety and functionality when doing basic repairs on commonly used APs. Like the user guide above, the manual could draw from the WHO GATE network's global research and be adapted to local contexts. DPOs and AT users could distribute the manual.
6. *Compiling resources on AT providers and service providers.* Though there are a range of DPOs, informal enterprises, and traders specialising in AP sales and AT services, knowledge about them and the services and products they offer is generally through word of mouth and often intermittent and out of date. As a result, both AT users and organisation acquiring APs for donation have limited and unpredictable information about where to access particular APs and AT services. Simple approaches such as a WhatsApp group or other appropriate local digital networks could help share this information.



## Appendix 1: FGD and semi-structured interview guide

Appendix 1: Topic guide per research activity	
Activity/Research respondents	Questions/Methods per activities (spread across the domains in Table 1, above)
FGDs with AT users and those with unmet AT need	<p>Divide respondents into groups according to functioning domain (e.g. hearing, mobility, visual. etc).</p> <ol style="list-style-type: none"> <li>1. Ask each group to choose five pieces of 'equipment' that they think are most helpful or important for them to do their daily activities. Write them on 5 post-it notes.</li> <li>2. Ask them to rank these five items from most to least important. <i>Output: one flipchart page with five items ranked most to least important.</i></li> <li>3. Ask them why they chose the top one as the most important.</li> <li>4. For the item(s) that they ranked as most important, ask them for all the places/organisations in and around their city where they can acquire this item. <i>Output: flipchart with a list of all the place and organisations.</i></li> </ol> <p>Ask them how they heard about these organisations.</p> <ol style="list-style-type: none"> <li>5. Write up a list of the criteria for what makes a service provider good or bad: price, location, speed of service, quality of product, customisability, durability, ease of repair, appearance, comfort</li> </ol> <p>Ask them to add any criteria that we did not list.</p> <ol style="list-style-type: none"> <li>6. List the organisations from the last flipchart that score the best against each criterion.</li> <li>7. Ask them to circle the three criteria that are most important to them when they were choosing their AT/ this item. <i>Output: flipchart with the list of criteria and who scores highest for each, with their top three criteria circled.</i></li> </ol> <p>Ask why these three criteria are most important for you.</p>
FGDs/interviews with groups that represent AT users: <ul style="list-style-type: none"> <li>• DPOs</li> <li>• Organisations representing (potential and actual) AT user groups, such as older people's organisations and veterans' organisations,</li> <li>• Urban poor community-based organisations</li> </ul>	<ul style="list-style-type: none"> <li>• How does the group define 'informal markets'?</li> <li>• What are the main APs that users access through informal markets?</li> <li>• What kind of informal enterprises make, supply, or service (prescription, fitting, repair) the key APs?</li> <li>• To what extent are public policies on AT access enacted and accessible to low-income populations</li> <li>• and are low-income populations aware of them?</li> <li>• How do people accessing or maintaining AT through informal markets finance APs and related services?</li> </ul>



<p>FGDs/ Interviews with formal government AT stakeholders: – specific stakeholders to be identified through liaison with CHAI country teams</p>	<ul style="list-style-type: none"> <li>• How does the group define ‘informal markets’?</li> <li>• What are the main ATs that users access through informal markets?</li> <li>• Which government organisations work on the regulation of informal markets, including sectors related to AT (e.g. second-hand goods trade, manufacturing, traditional healers, etc.)?</li> <li>• What are the key public policies, including CRPD, that determine access to AT?</li> <li>• (How) do they extend access to those living in informal contexts (e.g. residents of informal settlements, unregistered workers)?</li> <li>• Are there norms or guidance on product standards or specifications that influence formal AT production and services? (How) are these regulated?</li> <li>• What are the key finance schemes for APs? (How) do official finance schemes for AP access and services enable access for informal users (e.g. informal settlement residents, unregistered workers)?</li> <li>• What guidance (if any) is given to AT users about minimum AT product or service standards that they should look for from providers, including informal providers?</li> <li>• (How) does official government data collection on disability pick up or exclude AT users and potential users in informal settlements?</li> <li>• Does government data on AT recognise or cover informal markets? If so, how?</li> </ul>
<p>Interviews with AT users spread across life course and product domains (vision, hearing, intellectual, mobility, communication). These focus groups explore the quality of AT and AT services accessed through informal markets (for a defined number of core APs) and experiences of use and relevance to context.</p>	<ul style="list-style-type: none"> <li>• What do participants understand as informal AT providers?</li> <li>• What are the main APs that they access through informal markets?</li> <li>• Are they aware of any legal rights they have to support in accessing AT?</li> <li>• Are they able to access these rights in practice? If not, why not?</li> <li>• Where did they access their main APs?</li> <li>• Where did they get AT services (prescription, fitting, repairs)?</li> <li>• What is their view of the quality of their AP and AP services from different distributors and providers?</li> <li>• How did they finance their AT and what help did they get?</li> </ul>
<p>Interviews with AT producers and service providers to capture wider informal AT producers not linked to specific market systems.</p>	<ul style="list-style-type: none"> <li>• In what ways do participants interact with formal government stakeholders or other actors (e.g. NGOs)? What forms of regulation are they subject to in practice?</li> <li>• Are they aware of any AT norms or standards?</li> <li>• Where do they acquire skills and training?</li> <li>• What, if anything, are they able to do to support access to low-income and vulnerable AT users?</li> </ul>

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