

# Assistive Technology in urban low-income communities in Sierra Leone & Indonesia

Rapid Assistive Technology Assessment (rATA) survey results

January 2022



This study was led by Ignacia Ossul Vermehren and Julian Walker (Bartlett Development Planning Unit, University College London, DPU-UCL). The Sierra Leone surveys were carried out by Hawanatu Bangura and Sulaiman Kamara (Sierra Leone Urban Research Centre: SLURC), with a data collection team from FEDURP (The Sierra Leone Federation of the Urban and Rural Poor), led by Yirah O'Conteh. The Indonesian survey was carried out by Ahmad Rifai, Fuad Jamil and Nina Asterina (Yayasan Kota Kita), Fitria Ramadhini (Kaki Kota), and Kesuma A. Yanti (Former Researcher, Kaki Kota). Giulia Barbareschi and Cathy Holloway (Department of Computer Science, University College London) adapted the rATA survey for the Kobo Collect app, and codes were adapted and updated in the field by Wesley Pryor (Nossal Institute for Global Health, University of Melbourne). Mark Carew and Ellie Cole (Leonard Cheshire) performed statistical analysis. The study was part of the AT2030 Programme, led by the GDI Hub, and funded by the UK Foreign, Commonwealth and Development Office (UK FCDO).

#### To cite this publication please use the following reference:

Ossul-Vermehren, I., Carew, M.T. and Walker, J. (2022). Assistive Technology in urban low-income communities in Sierra Leone and Indonesia: Rapid Assistive Technology Assessment (rATA) survey results. Bartlett Development Planning Unit - Global Disability Innovation Hub, London.

#### **Acknowledgements:**

The authors would like to thank the residents of Pelambuan and Kelayan Barat in Banjarmasin, Indonesia; Dworzark, Thompson Bay, and HEPPO in Freetown, Sierra Leone for taking part in the survey, as well as the data collectors from Kota Kita, Kaki Kota, FEDURP and SLURC. Thanks to Giulia Barbareschi and Cathy Holloway (Department of Computer Science, University College London) for their feedback and adapting the Kobo Collect survey on the app; Victoria Austin (Global Disability Innovation Hub) for the feedback on the survey; Wesley Pryor (Nossal Institute for Global Health, University of Melbourne) for evaluating the training in Sierra Leone and updating the field codes in the field; and Wei Zhang and Emma Tebbutt (World Health Organization) for their support in the overall implementation of the rATA.

Graphic design and data visualisation: Lea Riggi.



This document is an output of a project funded by UK aid from the Foreign, Commonwealth & Development Office (FCDO), for the benefit os developing countries. The views expresseed are not necessary those of FCDO.



Data collection for this project was funded by the AT2030 Programme, which tests new approaches to find "what works" in the assistive tech (AT) field. Through six strategoc streams, the AT2030 Programme is working with the world's best innovatros to pioneer new ways of doing things in AT.

The Bartlett Development Planning Unit of University College London (DPU-UCL) 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. See: https://www.ucl.ac.uk/bartlett/development/

**Leonard Cheshire** is a non-profit organization which supports people to live, learn and work as independently as they choose, whatever their ability. In the UK and around the world, Leonard Cheshire works with partners to open doors to opportunity and break down barriers that deny people with disabilities their basic rights. See: www.leonardcheshire.org

The Sierra Leone Urban Research Centre (SLURC), based in Freetown, is a globally connected research centre created by 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 low-income communities in cities across Sierra Leone. See: https://www.slurc.org/

The Federation of Urban and Rural Poor (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. See: https://codohsapa.org/

**Kota Kita** is a non-profit organization based in the Indonesian city of Solo, with expertise in urban planning and citizen participation in the design and development of cities. Kota Kita provides education, facilitates citizen participation and collective action, and works with governments to build bridges between officials and their constituencies. See: https://www.kotakita.org/

**Kaki Kota** is a non-profit organization based in Banjarmasin, Indonesia, committed to the co-production of knowledge and ideas from citizens. Kaki Kota works with communities to generate innovative knowledge and practices to build sustainable cities and regions. See: https://www.instagram.com/kakikotaorg/?hl=en

The **Global Disability Innovation Hub (GDI 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 people with disabilities and the expertise of practitioners, academics, and local communities. See: https://www.disabilityinnovation.com/and: https://at2030.org/

## **Executive summary**

World Health Organization (2021). Assistive Technology fact sheet. <u>Source</u>

> Groce, N., and Kett, M. (2013). The Disability and Development Gap (Working Paper No. 21). Leonard Cheshire Disability. Source

> > 0.3

See: Walker, J., Rifai, A., Jamil. A., Kurniawan V. (2020 a). Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Indonesia. Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub. Also: Walker, J., Sallam, N., Sesay S., and Gandi, I. (2020 b). Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Sierra Leone. Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub

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According to the World Health Organization (WHO), 15% of the population has a disability and more than a billion people need one or more assistive products (AP), but only one in ten people have access to the devices they need. The WHO project that the need for AP will increase rapidly with ageing populations and growth in noncommunicable diseases, so that more than two billion people will need at least one AP by 2030.1

However, while the prevalence of disability and need for Assistive Technology (AT) - which comprise assistive products and their related services - have been documented in general terms, there is little data on low-income settlements in the global south. This is an important hiatus, given the close association between disability and poverty.2 In the global south, many AT users must pay for access to AT.3 Therefore it is to be expected that residents of lowincome settlements in the global south face particular challenges in accessing AT.

To contribute to this knowledge gap, the findings from the surveys presented in this report give a unique insight into disability prevalence and access to AT in five urban low-income communities in Sierra Leone and Indonesia, where a total of 4,256 individuals were surveyed using the rATA tool.4 Designed for the rapid evaluation of the need, use, supply and impact of AT, Rapid Assistive Technology Assessment (rATA) is a new survey from WHO. A version modified by the Development Planning Unit-University College London (DPU-UCL) was conducted in September 2019 for the research project "AT2030" community led solutions",5 as part of the AT2030 programme led by Global Disability Innovation Hub.

Data was collected using KoBoTool box, a suite of smart phone tools for data collection and analysis,

especially within challenging environments. Using a population survey approach, the five low-income urban communities where the rATA was conducted included: Thompson Bay, Dworzark and Help Empower Polio Persons Organization (HEPPO) in Sierra Leone, Kelayan and Pelambuan in Indonesia.

Four of the sites (Dworzark and Thompson Bay in Freetown, and Kelayan Barat and Pelambuan in Banjarmasin) were selected as 'mainstream' settlements the urban poor. The intention was to understand the need for and access to AT in settlements occupied largely by low-income people without specific provisions for, or particular visibility of, people with disabilities. In contrast. the fifth settlement, HEPPO in Freetown, was a unique case study for researching AT access in Sierra Leone. It is community organised around wheelchair users and people affected by polio.

The findings in the four mainstream communities showed a high disability prevalence (using the "some difficulty" or above cut-off): 20.6% in Thompson Bay and Dworzark, Sierra Leone; and 30.9% in Kelayan Barat and Pelambuan, Indonesia. **Severe disability** prevalence ("a lot of difficulty" or above) was 4.3% to 7.0%, respectively.

The most common impairments were related to mobility and seeing/vision. The least common impairments were speaking or communicating, and remembering or concentrating, however their prevalence rose significantly in older people.

More than half of the older population had a disability (62.5% in Thompson Bay and Dworzark, Sierra Leone and 69.4% in Kelayan Barat and Pelambuan, Indonesia) among whom most were severely disabled, indicating that the environment<sup>6</sup>

Acquired vs hereditary health condition

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Data collectors interpreted 'informal providers' as shops or enterprises that are not legally registered as AT providers, including local markets and unregistered shops, tradespeople such as mechanics and carpenters, and, in Sierra Leone, the large second-hand goods markets

Research suggests that self-reported surveys often fail to correspond well to clinical assessments, featuring significant elements of both under- and over-reporting of need for AT. Boggs, D. et al. (2021). 'Estimating Need for Glasses and Hearing Aids in The Gambia: Results from a National Survey and Comparison of Clinical Impairment and Self-Report Assessment Approaches'. International Journal of Environmental Research and Public Health, 18 (12). 6302. Source

plays an important role in disability prevalence. Females tended to have slightly higher disability prevalence than males (21.6% vs 19.5% in Thompson Bay and Dworzark, Sierra Leone; 34.9% vs 27.1% in Kelayan Barat and Pelambuan, Indonesia), had less AP coverage, and more selfreported AP need.

coverage was low among the population in need (14.9% in Thompson Bay and Dworzark, Sierra Leone and 47.4% in Kelayan Barat Indonesia), and Pelambuan, the variety of devices found was extremely limited, with most being spectacles (81.0% in Thompson Bay and Dworzark, Sierra Leone and 93.8% in Kelayan Barat and Pelambuan, Indonesia). Self-caring devices were a priority in all the case studies, and more than half of the respondents that had a difficulty in self-caring said that they did not have the AP they needed (52.9% Thompson Bay and Dworzark, Sierra Leone; 46.7% Kelayan and Pelambuan, Indonesia). Seeing/vision devices were a priority in Thompson Bay and Dworzark, Sierra Leone (56.6%), and speaking or communicating devices (41.9%) were a priority in Kelayan Barat and Pelambuan, Indonesia.

Most AT users got their AP from the informal sector<sup>7</sup> (30.8% in Thompson Bay and Dworzark, Sierra Leone; 65.3% Kelayan and Pelambuan, Indonesia). The majority of APs accessed through informal providers were spectacles. Most AT users had to pay for their AP, and when interviewees were asked why they did not have the AP they need, affordability was the most frequent reason given in all the settlements. In general AT users were fairly satisfied with the quality of the AP they had, but were less satisfied with maintenance and services.

The rATA findings in HEPPO, the community organized by wheelchair users, showed that there was extremely high prevalence of severely disabled adults with a mobility impairment (29.9%). There was, however, also very high AP coverage (71.4%) among the population in need. The most common APs were wheelchairs and tricycles, and most APs came from non-governmental organizations (45.4%). This coverage contrasts starkly with the low coverage found in the other communities in Sierra Leone, where only 14.9% of the population in need had an AP. However, satisfaction with current devices was relatively low (68.6% reported that the device was "moderately" suitable for their environment and 87.1% that it was "moderately" helpful for everyday activities). Self-reported need for AP was extremely high (73.5%), particularly for self-caring devices (86.4%). Further research into this community could help understand better how urban low-income communities can develop support mechanisms to advocate for ATs. It may also give insights into how to improve access to information, secure devices and address stigma around AT.

The findings from the rATA are an important first step in addressing the gap in quantitative data on disability prevalence and the access to AT in urban low-income communities. Unlike other population survey tools addressing AT need that are based on clinical assessment, the rATA survey draws on respondents' self-reported perceptions of AT need and their experiences of AT access and use.8 The advantages of a self-reported survey like the rATA are that it is rapid and low cost, uses consistent and comparable survey elements, and brings in AT users' own perspectives and experiences. In the absence of clinical assessments of AT need in the two cities, the rATA is an important contribution to highlighting locally perceived patterns of AT need and access.

## Contents

	Key concepts & how they have been used in the report	p.10
01	Introduction	p.11
02	Scope & Methodology	p.14
03	Dworzark & Thompson Bay, Sierra Leone	p.20
04	HEPPO (Help Empower Polio Persons Organization), Sierra Leone	<b>p.3</b> 5
05	Kelayan Barat & Pelambuan, Indonesia	p.50
06	Overall findings	<b>p.</b> 66
	Appendices	p.73

#### 7

### List of tables

Table 1	Overview of the rATA	16
Table 2	Sites and population surveyed in Banjarmasin (Indonesia) and Freetown (Sierra Leone)	19
Table 3	Age of onset for severe disability in Thompson Bay and Dworzark	27
Table 4	Age of onset in Pelambuan and Kelayan Barat	57
Table 5	Total APs found in the general population in the three cases	70
Table 6	Self-reported need of appropriate APs by order of priority in the three case studies	70

## **Appendices**

Appendix 1	rATA poster of 26 prioritised assistive products	73
Appendix 2	Rationale for the modification of WHO rATA by DPU-UCL	74
<b>Appendix 3</b>	rATA survey used by DPU-UCL (questions and instructions for data collectors in Kobo Collect)	78

## **Acronyms**

AP Assistive product

AT Assistive Technology

**DPU-UCL** The Bartlett Development Planning Unit, University College London

FEDURP Federation of the Urban and Rural Poor, Sierra Leone

GDI Global Disability Innovation Hub

**HEPPO** Help Empower Polio Persons Organization

**PWD** Person with Disabilities

rATA Rapid Assistive Technology Assessment

**SLURC** Sierra Leone Urban Research Centre

WHO World Health Organization

## **List of figures**

igure i	Data collectors from FEDORP conducting the rATA survey in Dworzark low-income community	13
igure 2	Location of the surveys using GPS from Kobo Collect	23
igure 3	Survey respondents in Thompson Bay and Dworzark by sex	<b>2</b> 4
igure 4	Survey respondents in Thompson bay and Dworzark by age group	24
		24
_		24
_	Disability prevalence ("some difficulty" and above) by age group in Thompson Bay and Dworzark	25
		25
_	Disability prevalence ("some difficulty" and above) between men and women across age groups	
		25
	Severe disability prevalence ("a lot of difficulty" and above) between men and women across	
Ū		25
iaure 11	Distribution of type of impairment amongst people experiencing "some difficulty" and above in	
<b>J</b> = -		26
iaure 12		27
_		27
		28
_		28
-		29
		29
		30
_		30
_		30
		30
_	Percentage of self-reported AP need by level of difficulty and by age group in Thompson Bay	
Ū		31
igure 23		31
_		31
_		32
_		32
_		32
_		32
		33
_		36
igure 31	Data collectors from FEDURP conducting the rATA survey in HEPPO during January 2020	37
igure 32	Survey respondents by sex in HEPPO	38
igure 33	Survey respondents in HEPPO by age group	38
igure 34	Total population surveyed by age group and sex in HEPPO	38
igure 35	Disability prevalence ("some difficulty" and above) in HEPPO	39
igure 36	Disability prevalence ("some difficulty" and above) by age group in HEPPO	39
igure 37	Severe disability prevalence ("a lot of difficulty" and above) in HEPPO by age group	39
igure 38	Disability prevalence ("some difficulty" and above) between men and women across age groups	
	in HEPPO	39
igure 39	Disability prevalence ("a lot of difficulty" and above) between men and women across age groups	S
_		40
igure 40	Distribution of type of impairment amongst people with "some difficulty" and above in HEPPO	40
_	Age of onset of people with a severe disability in mobility in HEPPO	
_	AP coverage by difficulty in HEPPO	
_	AP coverage by age group in HEPPO	42
iauro 44	AD aguarage by agy in LIEDDO	40

## Key concepts & How they have been used in the report

#### Age groups (children, working age and older people)

To analyse the data, respondents have been grouped into groups of nine years. For the findings, the age groups have been further grouped in three categories to aid dissemination: Children (age 0-19), working age (20-59) and older people (60+).

#### Age of onset

Age at which the respondent started experiencing "a lot of difficulties" or above in one or more domains, assessed through the question: "How old were you when you first began to experience a lot of difficulties?" The DPU-UCL team included this question in the rATA.

#### AP coverage (or AP prevalence)

Percentage of population in need of AT who have one or more APs. This indicator is useful for tracking progress towards the target of achieving universal access to APs.

#### Assistive product (AP)

"Any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual's functioning and independence, and thereby promote their well-being" <sup>9</sup>

#### Assistive technology (AT)

An umbrella term including assistive products and the related systems and services that support the delivery and use of AP.

#### **Disability prevalence**

Percentage of respondents that have a difficulty in one or more domains from the total surveyed. The questions in the survey were adapted from the Washington Group Short Set<sup>10</sup> and asked about the level of difficulty the respondents experienced performing the following six activities without an assistive product: Seeing, hearing, walking, remembering or concentrating, self-caring, speaking or communicating (e.g. "Do you have difficulty seeing without spectacles?") For the purpose of this report, the cut-off for disability has been established as follows:

**Disability**: People who reported "some difficulty", "a lot of difficulty" and "cannot do at all" in any one or more domains.

**Severe disability**: People who reported "a lot of difficulty" and "cannot do at all" in any one or more domains.

#### Population in need of AT

Respondents that have a difficulty in one or more domains. In the report, the population in need of AT is the same as the population that have a disability.

#### Self-reported AP need (or unmet need)

Assessed through the question: "Do you think you need any AP you don't currently have? If yes, which products in the poster do you need?" This is the percentage of respondents who reported that they did not have the AP they need from the population in need. Self-reported AP need differs from AP coverage: Self-reported is based on one question; and AP coverage is based on the AP found in the population.

09

World Health Organization, USAID and International Disability Alliance (2016). Priority assistive products list: improving access to assistive technology for everyone, everywhere. World Health Organization. Source.

10

See: Source

## **CHAPTER 1**

Introduction

### Introduction

11

The AT2030 Research Programme is funded by the UK Foreign, Commonwealth and Development Office (FCDO) and delivered by the Global Disability Innovation Hub (GDI Hub). Source

12

World Health Organization (2021). Assistive Technology fact sheet. <u>Source</u>

13

WHO (2021), op. cit.

14

World Health Organization and World Bank (2011). World Report on Disability. World Health Organization.

<u>Source</u> (page 101).

15

Nossal Institute for Global Health (2019). A Manual for Implementing the rapid Assistive Technology Assessment (page 8).

16

WHO and World Bank (2011), op. cit.

This report presents the findings of a series of Rapid Assistive Technology Assessment (rATA) surveys undertaken in September 2019 in three low-income communities in Freetown, Sierra Leone and two in Banjarmasin, Indonesia, during which a total of 4,256 individuals were surveyed. Designed for the rapid evaluation of the need, use, supply and impact of Assistive Technology (AT), the rATA is a new survey tool from the World Health Organization (WHO). The survey was undertaken for the research project "AT2030 Community led solutions", led by The Bartlett Development Planning Unit, University College London (DPU-UCL). The findings in this report contribute to addressing the current gap in quantitative data on disability prevalence and access to AT in low-income settlements in the global south.

It is estimated that by 2050, two billion people would benefit from AT, yet 90% will not have access<sup>12</sup>. The WHO defines AT as "the umbrella term covering the systems and services related to the delivery of assistive products and services", <sup>13</sup> and assistive products (AP) as "any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities." <sup>14</sup> Examples of AP are hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids.

It is important to note that "almost everybody will need AT at some point during their lives". <sup>15</sup> AT users are varied, and can include people with disabilities, people that have had an accident or illness, as well as older people. As the World Report on Disability <sup>16</sup> states, "Assistive technologies, when appropriate to the user and the user's environment, have been shown to be a powerful tool to increase independence and improve participation."

Addressing the large and growing unmet need for AT is central to meeting obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and in ensuring no one is left behind in achieving the Sustainable Development Goals (SDGs).

#### Why are the surveys important?

- The rATA makes an important contribution to highlighting locally perceived patterns of AT need and access: In contexts where it is difficult or expensive to conduct clinical assessments of AT need.
- They address the gap in quantitative data about disability in low-income communities: There is no global data on the prevalence of disability and/or coverage of AT in low-income communities.

- They provide data from a new survey on AT: Surveys about health and/or disability have rarely included questions about assistive products. The rATA is a new survey which addresses this gap, but has not yet been tested widely. For this project, the survey was piloted in Banjarmasin, Indonesia in May 2019 and modified by DPU-UCL, incorporating feedback given by users in low-income settlements and local organizations working with the urban poor.
- The rATA complements our previous qualitative study on the role of informal markets in Sierra Leone and Indonesia: To further understand the issue of access and maintenance of AT in informal contexts, two studies were conducted in Sierra Leone and Indonesia. Please find the two reports <a href="here">here</a>.
- The report provides unique data about a low-income settlement called HEPPO, primarily for wheelchair users: The rATA was implemented in a low-income settlement of people with mobility impairments resulting from polio in Sierra Leone.

#### Structure of the report

The report is divided into six chapters:

**Chapter 2** presents the scope of the studies and gives and overview of the rATA methodology.

The next three chapters discuss the findings of each of the case studies:

Chapter 3: Low-income communities in Freetown, Sierra Leone Chapter 4: Community of AT users in Freetown, Sierra Leone Chapter 5: Low-income communities in Banjarmasin, Indonesia

Each chapter works as a stand-alone piece for readers interested in a specific country/context. At the end of each chapter, the key findings of each survey are outlined. The findings are presented using the categories and order of the survey.

Overall findings are presented in **Chapter 6**, which explores the patterns that emerge from the three case studies.



#### FIGURE 1

Data collectors from FEDURP conducting the rATA survey in Dworzark low-income community during September 2019. Photo credit: Ignacia Ossul-Vermehren

## **CHAPTER 2**

Scope & Methodology

## Scope & methodology

#### rATA survey

These studies were undertaken using the WHO Rapid Assistive Technology Assessment (rATA) tool.<sup>17</sup> The WHO developed this survey tool because other surveys about health or disability rarely include questions about assistive products, or do not provide enough information to inform decision-making. The rATA aims to address that gap by providing a simple tool to determine answers to the most basic yet important questions about AT.<sup>18</sup> The survey is composed of five parts. The first collects d emographic information about the individual and is followed by three core data collection sections: need for AT, demand and supply, and satisfaction. There is a final optional section on recommendations. The survey includes a poster produced by the WHO Global Cooperation on Assistive Technology (GATE) programme, it includes images of 26 assistive products. The AP depicted relate to the areas of hearing, mobility, seeing, remembering or concentrating, self-caring, and speaking or communicating (**Appendix 1**).

The rATA survey has five broad sections covering: basic demographic information; disability prevalence/need for AT; demand and supply for AT; user satisfaction; and recommendations. The broad structure and focus of these sections are outlined in **Table 1**.

It is important to note that the rATA survey draws on respondents' self-reported perceptions of AT need, and their experiences of AT access and use. This is unlike other population survey tools for AT that are based on clinical assessment. The advantages of a self-reported survey like rATA are that it is quick and low cost, uses consistent and comparable survey elements, and involves AT users' own perspectives and experiences. However, research suggests that self-reported surveys often fail to correspond well to clinical assessments, featuring significant elements of both under- and over-reporting of the need for AT.<sup>19</sup> Despite this caveat, in the absence of clinical assessments of AT need in the two cities, the rATA has an important contribution to make in highlighting locally perceived patterns of AT need and access.

#### 17 See: Source

18

Nossal Institute for Global Health (2019), op. cit.

19

Boggs, D. et al. (2021). Estimating Need for Glasses and Hearing Aids in The Gambia: Results from a National Survey and Comparison of Clinical Impairment and Self-Report Assessment Approaches. International Journal of Environmental Research and Public Health, 18 (12). 6302. Source

#### TABLE 1

Overview of the rATA<sup>20</sup>

#### 20

Summary modified from material developed by the Nossal Institute of Global Health (2019), op.cit.

#### 21

The six questions are based on the Washington Group Short Set of Questions (WGSS), an internationally recognised disability questionnaire.

For further information, see: washingtongroup-disability.com/ The rATA survey differs from the normal application of WGSS questions, which asks people to report their level of difficulty despite using glasses for vision, in recognition that spectacles are a widely available AP.

Section	Outline of questions	Aim
Demographics	- Consent - About the household: Country, low-income community, geolocation and number of people living in the household About the respondent: Age, sex, date and time.	Gathers basic, anonymised data from respondents.
Disability Prevalence and need for AT	The six questions, based on the Washington Group Short Set of Questions <sup>21</sup> , ask about the level of difficulty the respondent has doing the following six activities without an assistive product: Seeing, hearing, walking, remembering or concentrating, self-caring, speaking or communicating (e.g. "Do you have difficulty seeing without spectacles?"). For each one respondents can answer "no difficulty", "some difficulty", "a lot of difficulty" or "cannot do at all".	Determines functional difficulties experienced by respondent. Used to estimate prevalence of disability.
Demand and Supply of AT	- Current use of AT (identified from the list of WHO GATE or any others they have that are not on the list) For each AP the respondent currently has, the survey asks about: Source, payment and distance to access AT Self-reported AP need (e.g. "Do you think you need any AP you don't currently have? If yes, which products in the poster do you need need") and reasons for lack of AP.	Determines AP coverage in the population in need, self-reported need, and basic information about AP providers.
Satisfaction with AT	Satisfaction with: - Current products - Service quality - Follow up - Suitability of products - Effectiveness of products - Overall satisfaction with health and wellbeing	Provides information on the satisfaction of the AT user in relation to their assistive product, service, repair and maintenance.
Recommendations	Open-ended comments about improving access to AT in the country.	Solicits respondents' expertise and feedback about priority measures to improve AP services, quality

and access.

The rATA survey implemented by DPU-UCL is an adaptation of the original WHO survey. The following changes were made after piloting the survey in a low-income community in Indonesia, and receiving feedback from data collectors in both countries (see Appendix 2 for the modifications and Appendix 3 for the final survey). Key changes include:

- Informal providers: This survey has added a question on informal providers of AT, based on initial field observations that low-income urban residents in the two cities surveyed access many of their devices from the informal market. The specific implications of informal markets as AT providers are explored in two parallel reports.<sup>22</sup>
- Evaluation of specific ATs: This survey has changed the skip logic of the rATA tool to link qualitative evaluations (e.g. users' satisfaction with AP or associated services) to specific AP where respondents use multiple APs.
- Age of onset: This survey has added a question about the onset age for people
  with a severe disability to see if there is a relationship between access to AT
  and the age at which respondents started having difficulties.
- AT payment: The payment for AP question has been rephrased, to focus on what the AT user knows, instead of the sources of funding ("Did you have to pay for your AP?" instead of "Who paid for your AP?").
- AP poster: The original images by WHO were not organized by impairments and were only available on a mobile phone. DPU-UCL reorganized them by category to facilitate respondents' identification of the devices, and printed an A3 poster for each data collector.

#### Case studies

For this study, the rATA survey was conducted in five low-income urban settlements in the cities of Freetown (Sierra Leone) and Banjarmasin (Indonesia). These communities were selected as they are part of the wider research "AT2030: Community Led-Solutions". Given the strong association of disability with poverty, 23 and the challenges faced by people in need of AT living in contexts of poverty in the global south, 24 this project aimed to better understand the experiences of AT users, or those in need of AT, amongst low-income urban residents.

Accordingly, all five sites were identified by local partners (SLURC and FEDURP in Sierra Leone, and Kota Kita and Kaki Kota in Indonesia) as they work with the communities in a variety of ways, addressing poverty, low-income housing and public spaces, and citizen's participation among others. In the absence of sound local socio-economic data, that the settlements were identified as low-income communities by partners, and are current targets of interventions for the urban poor by the partners and local government, were taken as a proxy for low-income.

Four of the sites (Dworzark and Thompson Bay in Freetown, and Kelayan Barat and Pelambuan in Banjarmasin) were selected on the basis that they are 'mainstream' settlements of urban poor. This means that these settlements have no specific disability- related features, such as disability organizations or facilities, and do not have an unusually high concentration of persons with disabilities as residents.

#### 22

See: Walker, J., Rifai, A., Jamil. A., Kurniawan V. (2020 a). Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Indonesia. Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub. Source and Walker, J., Sallam, N., Sesay S., and Gandi, I. (2020 b). Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Sierra Leone. Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub. Source

#### 23

Groce, N., and Kett, M. (2013). The Disability and Development Gap (Working Paper No. 21). Leonard Cheshire Disability. <u>Source</u>

#### 24

Eide, A. H., and Øderud, T. (2009). Assistive technology in low-income countries. In Disability and international development (pp. 149-160). Springer, New York, NY. The intention was therefore to understand the need for and access to AT in average settlements occupied largely by low-income people, but without specific provisions for, or visibility of, people with disability.

The specific neighbourhoods in each city were also selected, in coordination with local partner organizations, to represent different geographies and cases in the city. In Freetown these included one coastal (Thompson Bay) and one hillside settlement (Dworzark), anticipating that these may be important factors for researching disability. In Banjarmasin, these included communities with different land tenures; one site which has not been prioritised for slum-upgrading (Pelambuan) as it is on private land, and another where the residents have secured recognised land tenure and have therefore been included in a slum-upgrading project (the national slum upgrade programme: KOTAKU).

The fifth community selected, HEPPO, in contrast, is an urban low-income community of primarily wheelchair users and people with mobility impairments resulting from polio<sup>25</sup> in Freetown. This community was included after the other four case studies in the wider research project, and the rATA survey was implemented here as a rare opportunity to deepen the understanding of access to assistive devices in an urban area which has been specifically developed by, and for, people with disability.

It is important to note that the findings do not claim to be representative of each city or country, but in the absence of national data on AT, the findings act as a sample survey which gives insights into patterns of AT access and use in low-income urban communities in the two countries. In this report we also share the demographics of the individuals surveyed, as there is limited data about these communities, and thus the information can be useful for actors working in these urban areas.

#### **Data collection**

The data was collected and stored using KoBoToolbox (https://www.kobotoolbox.org/), a suite of tools for data collection and analysis for use on a smart phone, especially within challenging environments. Using a population survey approach, the rATA was conducted in a specific area of each of the four mainstream communities selected during four weeks in September 2019. The aim was to survey 1,000 individuals within a defined area of the settlement using a population survey approach, hence everyone in a specific area. In Dworzark and Thompson Bay (Sierra Leone) 2,076 individuals were surveyed and in Pelambuan and Kelayan (Indonesia), 2,046 were surveyed. In HEPPO everyone from the community (134 individuals) were surveyed over six days in January 2020 (Table 2).

In Indonesia, 16 enumerators from NGOs Kaki Kota and Kota Kita participated in three-day training. The surveys were conducted during the day, and data collectors went back to households in the evening on multiple occasions (6-10pm) to pick up residents who had been absent during the day. In Sierra Leone, a team of twelve enumerators from the Federation of the Urban and Rural Poor (FEDURP) participated in three-day training conducted by DPU-UCL and SLURC that was evaluated by the Nossal Institute for Global Health for the WHO. The survey was conducted during the day (9am-4pm), and data collectors only went back to houses once during the same day to pick up residents who had been absent during the first visit<sup>26</sup>.

25

Poliomyelitis is a highly infectious disease caused by a virus, which mainly affects children under five years of age, and can lead to paralysis of the legs.

See more: Source

26

In Kelayan Barat and Pelambuan, 94% of the total people addressed answered the survey. In Dworzark and Thompson Bay the rate was 84%; and in HEPPO 100% of those addressed answered the survey. These included people that declined to provide consent and where no adult carers were present to interview children. In Sierra Leone there were more cases of there being no adults present (306 households) than in Indonesia (four households). In Sierra Leone, data collectors went back to houses once during the same day, while data collectors in Indonesia went back as many times as was necessary.

#### 19 I

#### TABLE 2

Sites and population surveyed in Banjarmasin, Indonesia and Freetown, Sierra Leone

#### 27

Statistics of Banjarmasin City (2018). Transportation Statistics of Banjarmasin Municipality 2018. <u>Source</u>

#### 28

YMCA Sierra Leone (2012). Vulnerability and Capacity Assessment of Dworzarck Community. Freetown, Sierra Leone. YMCA. <u>Source</u>

Country	Low-income communities	Criteria of selection	Total number of residents	Aim to survey	Total number surveyed	Response rate from individuals approached
Banjar- masin, Indonesia	Kelayan Barat	Mainstream settlement of the urban poor	6,763	1,000	1,020	94%
	Pelambuan	Mainstream settlement of the urban poor	12,854 <sup>27</sup>	1,000	1,026	94%
Freetown, Sierra Leone	Thompson Bay	Mainstream settlement of the urban poor	N/A	1,000	1,005	84%
	Dworzark	Mainstream settlement of the urban poor	16,500 <sup>28</sup>	1,000	1,071	84%
	Help Empower Polio Persons Organization (HEPPO)	Settlement of primarily wheelchair users and people with mobility impairments	134	All population	134	100%
Total surveyed					4,256	

The raw data was analysed by Leonard Cheshire and the statistical report was written by DPU-UCL and Leonard Cheshire, with feedback from WHO.

Ethical approval for the study was granted by UCL. Consent from participants was sought after a three-minute information video which was shown to everyone on a phone (including subtitles). Each video was prepared considering the cultural differences of each country in terms of language and image type. A sign language interpreter was present in case of respondents that needed this service. Children and young people under age 17 were only interviewed with a carer present, and if not, they were not interviewed. Responses for children between 0-9 years were given by a proxy adult. People with disability who needed a carer to help them communicate were interviewed directly, with a carer present.

The implementation of the rATA through grassroots organizations benefited the wider research in two ways:

- The survey involved grassroots organizations (i.e. FEDURP, Kaki Kota) working on urban issues in disability.
- The survey acted as a basis to train and raise the awareness of local organizations about the existence of a diverse range of AP and the importance of AT.

## **CHAPTER 3**

Dworzark & Thompson Bay, Sierra Leone

## **Dworzark and Thompson Bay, Sierra Leone**

#### Context

#### Disability and Assistive Technology in Sierra Leone

Sierra Leone, located in West Africa on the coast of the Atlantic Ocean, has a total of seven million inhabitants, one million of whom live in Freetown, the country's capital.<sup>29</sup> 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. According to the accompanying thematic report,<sup>30</sup> 93,129 people in the country, or 1.3% of the population, have a disability. This is an unusually low disability prevalence, and though the census represents the most comprehensive overview on disability, national disability stakeholders involved in the AT2030 research project, including DPO representatives, have argued that it underestimates the true prevalence of disability in the country.<sup>31</sup> This finding justifies the implementation of the rATA in low-income communities in Sierra Leone, as it gives a fresh indication of disability prevalence. Different to the census, in which disability is asked about directly, the rATA only asks about functioning, which may avoid some of the stigma associated with a person self-defining as 'disabled'.

According to the census, more males than females have a disability (male 54% - female 46%), with a large portion between the ages of 20 and 50 (45%). 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 picked up in the census indicates that the most common disability type is physical (mobility) impairment, followed by visual impairments. Disease or illness is the major cause of disability among the country's disabled population, accounting for 40.5% of cases.

In Sierra Leone, there is no comprehensive source of data about the availability of AP. The Sierra Leone Disability Act of 2011 defines AT as "assistive devices and services" such as "carers, implements, tools and specialized services provided by people to persons with disability to assist them in education, employment or other activities." As DPU-UCL research showed, some of the main providers of AT are non-state actors, and databases are often maintained on an organizational basis and rarely shared externally (as is the case with NGOs). 32

29

Statistics Sierra Leone (2015). 2015 Population and housing census key figures. Statistics Sierra Leone. <u>Source</u>

30

Kabia, F. and Tarawally, U. (2017). Sierra Leone 2015 Population and Housing Census. Thematic Report on Disability, Freetown, Sierra Leone. Statistics Sierra Leone. Source (Last accessed 05/01/2020)

31

Walker et al. (2020 b), op. cit.

32

Walker et al. (2020 b), op. cit.



Data collector from FEDURP conducting the rATA survey in Dworzark low-income community during September 2019. Photo credit: Ignacia Ossul-Vermehren

#### **Dworzark low-income community**

Dworzark is a hillside settlement, located 5km from Freetown's city centre. It is divided into twelve sections and has been populated since the 1940s. There has been rapid urbanization in the area since the 1980s, leading to the expansion of the uphill parts of the settlement. The 313-acre settlement contains 5,236 households.<sup>33</sup> Land in the settlement is composed of a steep hillside and features large rocks or boulders over-hanging buildings.

Land ownership is 50% private, 25% municipality, and 25% customary land. About 3.5% of the land area is occupied by the Sierra Leone Bottling Company, which acquired the land from the Dworzark family in the 1950s. Housing is built of mud bricks and corrugated iron sheets, connected by unpaved road networks. The drainage system is poor and many households fetch water from beneath boulders. The community has about twelve public toilets used every day by more than 2,500 people. There is no connection to the main city water pipeline, and only 20 public water points which serve more than 4,000 residents every day. Residents depend on the George-Brook Stream, wells and spring water for their daily water needs. The community has one formal market, twelve schools and one health centre. The characteristics and location of the settlement make it prone to socio-environmental risks, including fires, floods, rock falls, and outbreaks of waterborne diseases. Although the number of fatalities from these risks appears to be relatively low (barring the 2014 Ebola outbreak), cumulative vulnerability in the settlement is significant.<sup>34</sup> Most women are petty traders engaged in "table-top businesses", or home-based enterprises, with few in formal employment.

#### 33

CODOHSAPA and FEDURP (2011).
Community-Led Enumeration and
Profiling: The State of 11 Coastal Slums
in Freetown, Sierra Leone. Source

#### 34

Koroma, B., Rigon A., Walker J. and Sellu S. A. (2018). Urban livelihoods in Freetown's Informal Settlements. <u>Source</u>

#### FIGURE 2

Location of the surveys using GPS from Kobo Collect. Thompson Bay is a coastal settlement (left) and Dworzark is located in a hilly area (right), both arelocated on the west side of Sierra Leone's capital city Freetown



Due to the historic availability of rocks as an open-access resource, stone quarrying is an established livelihood in the community in which more than 500 residents are currently involved (Koroma et al. 2018). Social programmes in the community include a cash transfer project by the National Commission for Social Action (NACSA); a savings and loans project by FEDURP; drainage works by the Freetown City Council, Catholic Relief Services, and Concern Worldwide; and waste-to-wealth initiatives by UNDP. These interventions do not specifically address disability issues or promote Assistive Technology.

#### **Thompson Bay low-income community**

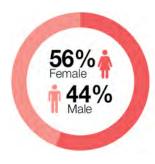
Thompson Bay is a seaside settlement approximately 10km from Freetown city centre which has been populated since the late 1990s. The density of households has been increasing, and the settlement now contains about 1,624 households (CODOHSAPA and FEDURP 2011). The community is situated in a wetland (a mangrove swamp) that has been banked up over the years for the construction of homes. Land is 100% state-owned, so tenure is insecure with threats of eviction increasingly imminent. Most of the land area is used for residential purposes, with a small portion used for a food market, road construction, school, and a mosque. The settlement is characterized by a mix of well-designed concrete, and poorly constructed, housing, with fairly good road networks. Water is rationed with almost no home receiving a 24-hour supply, and consequently there is limited access to safe drinking water. Sanitation is poor and there are no councildesignated waste dumps. The community has a food market, mosque, school, and a health centre which was previously demolished following a land dispute. The features and location of the settlement make it prone to flooding (being on the shoreline and serving as a major outlet for drainages from surrounding communities that are located uphill), and outbreaks of waterborne diseases (from the inadequate treated water supply, and solid waste disposal in drains and the stream). Many of the male residents are fishermen and sand miners, while most of the women are petty traders. Sand mining is a common practice during low tides in the lagoon neighbouring the community. Petty trading is done either on table-tops, in home-based enterprises, or kiosks located along strategic streets in the community. Actors intervening in the community include Action Aid, Action Contre Le Faim (ACF), Freetown City Council, Kiva, BRAC, World Hope International, and Concern Worldwide. Their interventions do not specifically address disability issues or promote Assistive Technology, but do provide social services (such as social transfers) that benefit people with disabilities.

#### 24

## 1. Thompson Bay and Dworzark's demographics

#### FIGURE 3

Survey respondents in Thompson Bay and Dworzark by sex



The 2,076 individuals surveyed were distributed across 815 households.<sup>35</sup> The household composition ranged from one to 16 members, and the average number of household members was five. From the total number of respondents, 55.7% were women and girls and 44.3% were men and boys (**Figure 3**).

#### **FIGURE 4**

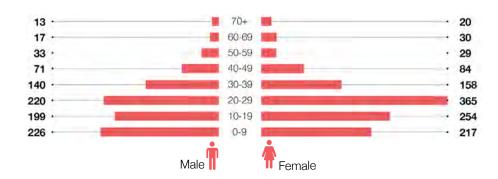
Survey respondents in Thompson Bay and Dworzark by age group



The population surveyed in Thompson Bay and Dworzark was young; 23.71% of the population was below 29 years old and only 4% of the population was older than 60 years. In terms of age groups, there were similar numbers of children (0-19) and working age people (20-59) (**Figure 4**). Women between ages 20-29 made up the largest group (365 women), followed by girls age 10-19 (254 girls) (**Figure 5**).

#### FIGURE 5

Total population surveyed by age group and sex in Thompson Bay and Dworzark



#### 35

The identification of individual households in low-income communities in Freetown is difficult due to the unplanned nature of the area and the heterogeneity of family units/types of housing. During the training sessions in September 2019, FEDURP and SLURC defined a household, for the purpose of this survey, as "a group that sleeps and cooks together, independent of the housing structure".

#### 2. Disability prevalence and need for AT

### 2.1. There was a high prevalence of disability in the two neighbourhoods (Figure 6)

20.6% (or 429 people) of the respondents have "some difficulty" or more seeing, hearing, walking, remembering or concentrating, self-caring, speaking or communicating. Of these, 4.3% (91 people) have a severe disability, experiencing "a lot of difficulty" and "cannot do at all" in one or more domain.

#### FIGURE 6

Disability prevalence ("some difficulty" and above) in Thompson Bay and Dworzark



There was a higher prevalence of disability among older people than children and the working age population (Figure 7): The findings show a sharp age gradient in disability prevalence, 13.5% of children reported "some difficulty" or above while that figure rises to 23.5% in working age people, and to 62.5% in older people.

FIGURE 7

Disability prevalence ("some difficulty" and above) by age group in Thompson Bay and Dworzark



There was a higher prevalence of disability among girls and women (21.6%) than their male counterparts (19.5%) (Figure 8): 21.6% (250 people) females have a disability, as opposed to 19.5% (179 people) males. For severe disability, females and males have similar prevalence, with 4.3% of females and 4.5% of males declaring having "a lot of difficulty" and above in any one domain. Males tend to have a higher disability prevalence than women in older age (84.6% of males age 70+, 70.0% of females). However, females have a higher prevalence of severe disability in this age bracket (females age 70+ 35.0%, and males 23.1%) (Figure 9 & Figure 10).

**Dworzark had higher disability prevalence than Thompson Bay:** The prevalence of disability in Dworzark is 25.9%, while in Thompson Bay it is 15.1%. The most important difference is in the domain of seeing/vision. In Dworzark there are almost three times more cases of difficulty seeing/vision than in Thompson Bay (41 vs 16 people).

#### FIGURE 8

Disability prevalence by sex in Thompson Bay and Dworzark

#### FIGURE 9

Disability prevalence ("some difficulty" and above) between men and women across age groups in Thompson Bay and Dworzark

#### FIGURE 10

Severe disability prevalence ("a lot of difficulty" and above) between men and women across age groups in Thompson Bay and Dworzark



#### 2.2 Seeing and mobility were the most common impairments

There were 620 impairments amongst the 429 people that reported having a difficulty, indicating that some people have difficulties in more than one domain. One third of the impairments reported were in the domain of seeing/vision (35.3%) and one third in mobility (33.9%), followed by remembering or concentrating (10.5%). The least prevalent impairment was self-caring (5.5%) (**Figure 11**).

#### FIGURE 11

Distribution of type of impairment amongst people experiencing "some difficulty" and above in Thompson Bay and Dworzark



**Seeing/vision (35.3%):** Of the people that have difficulties, more than a third of these are with seeing. Difficulty in seeing increases consistently with age, both in men and women, however men over 70 years old show the most difficulty. Eight out of 10 have "some difficulty" or more seeing (84.6%), as do half of women (50%) in this age bracket.

**Mobility (33.9%):** Of the people that have difficulties, more than a third involve moving. Like vision, mobility difficulties increase consistently with age, both in men and women. However, men over 70 years old have the most difficulty. Seven out of 10 men have "some difficulty" and above (69.2%), as do five out of 10 women (45%) in this age bracket.

**Remembering or concentrating (10.5%):** Of the people that have difficulties, 10.5% concern remembering or concentrating. Females between 60-69 years have the most difficulties in this domain (five females or 16.7%).

**Hearing (8.7%):** Of the people that have difficulties, 8.7% are in the domain of hearing. Males over 70 years old experience the most difficulty hearing (15.4%).

**Speaking or communicating (6.1%) and self-caring (5.5%):** These are the least common impairments. 38 people reported having difficulties speaking or communicating, and 34 had difficulties self-caring. Their prevalence increases in older people.

### 2.3. Most people that have a severe disability acquire it as an adult, on average between the ages of 17.5 and 52 years (Table 3)

Impairments acquired at younger ages include difficulty hearing (17.5 years old) and speaking or communicating (20 years old). Self-caring (41 years old) and remembering or concentrating (52 years old) tended to be acquired at an older age. Seeing (at 22 years old) and mobility (at 38 years old) - the most common impairments in both communities - are in the middle of the age brackets.

Severe disability ("a lot of difficulty" and more)	Age of onset (Median)	Number of people
Hearing	17.5	3
Speaking or communicating	20	7
Seeing/vision	22	57
Mobility	38	30
Self-caring	41	7
Remembering or concentrating	52	4

TABLE 3
Age of onset for severe disability in
Thompson Bay and Dworzark

#### 3. Demand and supply of AT

#### 3.1. AP coverage was extremely low in the two communities

Only 14.9% of the population that has a difficulty has at least one device they need, while 85.1% do not have any AP (**Figure 12**).

People with "some difficulty" have the least coverage (**Figure 12**). Only 9.8% or 33 people that experience "some difficulty", about a third of individuals who experience a lot of difficulty (35.4% or 29 people), and just over a fifth who cannot function at all (22.2%; two people) have AP coverage. It is worth highlighting that the lack of access to AT is worse for those who "cannot do at all" than it is for those who experience "a lot of difficulty".

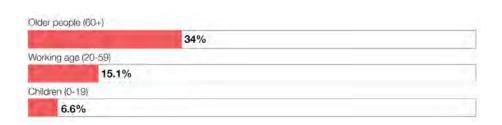
## FIGURE 12 AP coverage by type of difficulty in Thompson Bay and Dworzark



Children have the least AP coverage (only 6.6%), while older people have the highest AP coverage (34%). However, this number is still very low (**Figure 13**).

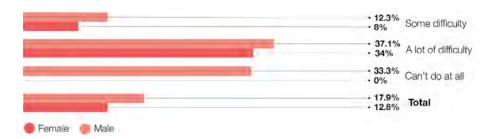
#### FIGURE 13

AP coverage by age group in Thompson Bay and Dworzark



Women and girls have less AP coverage (12.8%) than men and boys (17.9%) (**Figure 14**).

## FIGURE 14 AP coverage by sex in Thompson Bay and Dworzark



Respondents in Dworzark have better AP coverage (18.4%) than those in Thompson Bay (8.6%) (**Figure 15**).

#### FIGURE 15

AP coverage by neighbourhood



#### 3.2. The variety of AP in use is low

The survey found only seven types of APs in use of those listed on the WHO GATE list of priority AP (which features 50 products), plus two instances of "Other" AP (Figure 16).

The total AP found in the two communities was 64 devices, 81% were spectacles: The AP divided in the following way: 52 spectacles, three auxiliary/elbow crutches, two canes/sticks, one tripod and/or quadripod, two manual wheelchairs (push type), one manual wheelchair (basic type), one therapeutic footwear, and one rollator/walking frame. There were two instances where participants listed products not present on the WHO GATE list of priority AP (one bandage and one incontinence product).<sup>36</sup>

36

The bandage was used by a male and the incontinence product by a female. They are not included in the figure, as these products are not part of the WHO GATE list of priority AP.

All the APs found related to mobility or seeing: No APs were found that related to hearing, communication, remembering and concentrating, and/or self-caring, despite there being people that have impairments in all of these domains.

Males' APs are more sophisticated and more varied than females': Males had six types of APs listed on the WHO GATE list of priority AP (spectacles, auxiliary/elbow crutches, canes/sticks, tripod and/or quadripod, push and basic type wheelchairs, therapeutic footwear and rollators/walking frame), while females only had three types (spectacles, auxiliary/elbow crutches and cane/sticks, tripods or quadripods). No female had a wheelchair, despite there being females with severe mobility impairments.

Male Female

81% Spectacles

23 29

Wheelchairs (basic & push type)

Auxillary/ elbow crutches

1 2

Cane/sticks, tripods,quadripods

1 1

Rollator/Walking Frame

Therapeutic footwear

There were two instances where participants listed products not present on the WHO GATE list of priority AP (Bandage & Incontinence product).

FIGURE 16

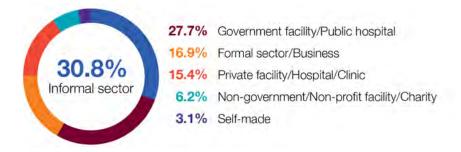
Type of assistive products found by sex in Thompson Bay and Dworzark

#### 3.3. The informal sector was the largest source of AP

One third (30.8%) of the respondents obtained their AP, mostly spectacles, from the informal sector, followed by government facilities or public hospitals (27.7%). Data collectors defined 'informal providers' as second-hand shops, street markets and street hawkers (**Figure 17**).

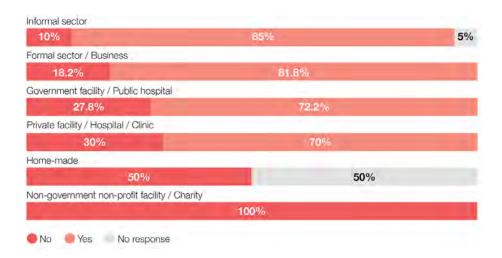
**Most AT users paid for their AP (70.7%)** (Figure 18): The only APs not paid for were those received from NGOs/charities (100%, four people), or those which were home-made (50%, two people).

FIGURE 17 Sources of AP owned by respondents in Thompson Bay and Dworzark



#### FIGURE 18 Payment of AP by type of provider in

Thompson Bay and Dworzark



#### 3.4. Almost half of the people with a disability do not currently have the AP they think they need (40.1% or 172 people) (Figure 19)

#### FIGURE 19

Self-reported AP need in Thompson Bay and Dworzark: "Do you think you need an AP you don't currently have?"



Self-reported AP need is higher in people that have more difficulties (Figure 20): 100% (nine people) of respondents that "cannot do at all" in any one domain said that they need an AP that they currently do not have. The type of difficulty is the clearest indicator of need for AP. Respondents with severe disabilities across all age groups and both sexes self-reported the greatest unmet need.

#### FIGURE 20

Percentage of self-reported AP need by level of difficulty in Thompson Bay and Dworzark



Self-reported AP need is higher in females (41.2%) than in males (38.5%) (Figure 21): Females self-reported more AP need than males amongst people

with "some difficulty" (Female 31% - Male 25.4%) and "a lot of difficulty" (Female 80.9% - Male 80%). Self-reported AP need is similar across ages (Figure 22).

#### FIGURE 21

Self-reported AP need by sex in Thompson Bay and Dworzark

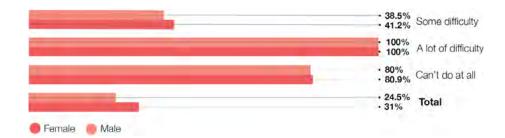
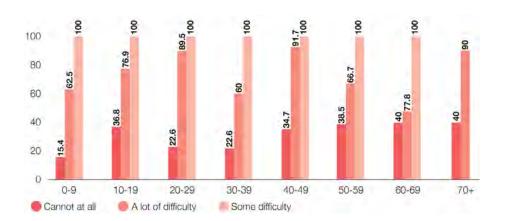


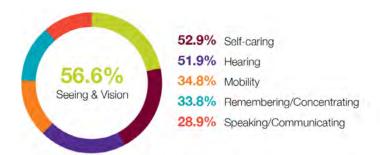
FIGURE 22
Percentage of self-reported AP need
by level of difficulty and by age group in
Thompson Bay and Dworzark



#### Self-reported AP need is highest among people that have difficulty seeing

(**Figure 23**): More than half of people (56.6% or 124 people) with difficulty seeing self-reported the need for AP; this was similar among those with difficulties in the domain of self-caring (52.9%, 18 people); and among those that have difficulties hearing (51.9%, 28 people). The impairment for which respondents self-reported the least need for AP was in speaking or communicating (28.9%).

FIGURE 23
Self-reported need of appropriate APs
in Thompson Bay and Dworzark



**Affordability is the main reason for not having an AP (80.5%):** Of the 172 individuals who self-reported AP need, the most common reason given was "lack of affordability" (80.5% or 140 answers), followed by "not being aware" (8.0% or 14 answers), and "not available" (5.0% or 4 answers). The least common answer was "lack of transport" (0.5% or 1 answer).

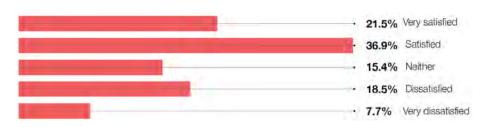
#### 4. Satisfaction

### 4.1. Respondents were generally satisfied with the quality and the maintenance of their APs.

**Overall satisfaction with the AP** (in terms of size, fit, comfort, weight, appearance, safety, and durability) (**Figure 24**): 64.7% of respondents were "satisfied" or "very satisfied" with AP quality, although women were less satisfied than men.

#### FIGURE 24

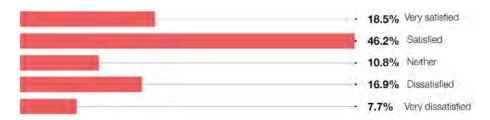
Overall satisfaction with AP in Thompson Bay and Dworzark: "Over the last month, how satisfied are you with your AP(s)?"



Quality of service while accessing AP (in terms of procedure, length of time or waiting period, quality of care and attention, and respectful of rights) (Figure 25): Almost half of the respondents (46.2%) were "satisfied" with the service.

#### FIGURE 25

Quality of services while accessing AP in Thompson Bay and Dworzark: "How satisfied are you with the quality of the service while accessing your AP(s)?"



AP repair, maintenance, and follow-up services: A third of respondents were "very satisfied" with the maintenance of their product (36.7%). Overall, men with the most severe disabilities were the most satisfied with the maintenance of their AP (ranking 4.17 or "quite satisfied" out of five for maintenance, where five is "completely satisfied") (Figure 26).

#### FIGURE 26

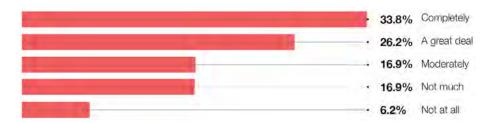
AP maintenance and follow-up services in in Thompson Bay and Dworzark: "How satisfied are you with repair, maintenance and follow-up services based on your last experience?"



Suitable for the environment (in size, fit, comfort and durability): A quarter reported that their product was "a great deal" suited to the environment (26.2%) and a third that it was "completely" suitable (33.8%) (Figure 28).

#### FIGURE 27

Suitability (in size, fit, comfort and durability) of AP in Thompson Bay and Dworzark: "Are your AP(s) suitable for your home or surrounding?"



Helpful (allows to do the everyday activities) (Figure 28): A quarter reported that their product helped "a great deal" (24.6%) and two-fifths said that it was "completely" helpful (40.0%).

#### FIGURE 28

Helpfulness (allows to do everyday activities) of AP in Thompson Bay and Dworzark: "Are you able to what you want to do when using your AP(s)?"



#### 5. Recommendations

**Recommendations from respondents about how to improve APs in Sierra Leone:** Respondents' answers divided into three types: the principle of universal access to AP, improved affordability, and a larger role for the government in improving access to, affordability and maintenance of the devices (**Figure 29**).

#### FIGURE 29

Recommendations from respondents about how to improve AP in Sierra Leone, open-ended answers "AP should be available for people with disabilities or that have been in an accident"

"The price of AP should be lower"

"The government should make these AP more accessible and cheaper"

## **Key findings from the rATA survey in Thompson Bay and Dworzark**

The population in Thompson Bay and Dworzark was very young: 71% of the respondents were under the age of 29. There was a larger proportion of girls and young women.

One fifth (20.6%) of the population had a disability and 4.3% had a severe disability: From the respondents that reported having a difficulty, one third (35.3%) had difficulties in seeing/vision and one third (33.9%) had difficulties with mobility. Most people that had a severe disability acquired it as an adult. Difficulty in seeing/vision was acquired on average (median) at the age of 22, and mobility at the age of 38.

There is a higher prevalence of disability among older people, but they also had the highest AP coverage: 62.5% of people over 60 had a disability, this was three times more than the working age population (23.5%). Men and women over 70 had a very high prevalence of difficulty in seeing/vision (males 84.6% - 50% females) and in mobility (males 69.2% - 45% females). Respondents over 60 years old had the best AP coverage (34%), although this coverage is still very low.

Females had higher disability prevalence than males, lower AP coverage, and self- eported more need for AP: Females have slightly a higher disability prevalence than males (females 21.6% - males 19.5%). They also had less AP coverage (females 12.8% - males 17.9%), and the AP they have was less sophisticated. Males had six types of APs, while females only had three types (spectacles, auxiliary/elbow crutches and cane/sticks, tripods or quadripods). No female had a wheelchair, despite there being females with severe mobility impairments. Self-reported AP need was also higher in females (41.2%) than in males (38.5%).

34

AP coverage was extremely low, and the variety of APs was limited: Only 14.9% of the disabled population had access to at least one device they needed, while 85.1% had no AP. Respondents that had "some difficulty" had the least coverage (only 9.8%). Even among those with "a lot of difficulty" that had the best coverage (35.4%), coverage remains very low. Interestingly, a smaller proportion of people who "cannot do at all" (22.2%) have access to AP than people with "a lot of difficulty". By age, older people had the best coverage (34%), while children had the least coverage (6.6%).

- The variety of devices was very low, the survey found only seven different types of APs (spectacles, auxiliary/elbow crutches, canes/sticks, tripod and/or quadripod, manual wheelchairs basic and push, and therapeutic footwear): All the devices relate to a mobility and seeing/vision impairment, despite there being people that have impairments in all the domains. 81.0% of the devices found were spectacles.
- Self-reported AP need was highest among respondents that have difficulty with seeing/vision: More than half of people (56.6%) with difficulty seeing said that they did not have the AP they need, followed by people with difficulties in self-caring (52.9%), and people with difficulties in hearing (51.9%). Most respondents (80.5%) said they did not have the AP they needed because they could not afford the device.

Most of the APs owned in Thompson Bay and Dworzark came from the informal market: One third (30.8%) of AT users obtained their AP, mostly spectacles, from the informal sector, such as second-hand shops, street markets and street hawkers. This was followed by government facilities or public hospitals (27.7%). Most users had to pay for their AP (70.7%), which were mostly spectacles bought in the informal market. The only APs not paid for were those received from NGOs/charities (100%), or those which were home-made (50%). Respondents were generally satisfied with the quality of their AP and the maintenance and follow-up services.

## **CHAPTER 4**

HEPPO (Help Empower Polio Persons Organization), Sierra Leone

## HEPPO (Help Empower Polio Persons Organization), Sierra Leone

#### **HEPPO Community**<sup>37</sup>

HEPPO is a community of people with disabilities and former street dwellers living in a land occupation in Freetown's city centre. It consists of 54 households each headed by residents who have had polio. According to Sierra Leone's 2015 Population and Housing Census,<sup>38</sup> the most common disability in the country (21.8%) is physical disability due to polio.

The settlement was initiated in 2000 when residents occupied vacant government-owned land. In 2013, residents created the organization HEPPO. The site, located in Brookfields next to Pademba Road Prison, was an abandoned building destroyed during the war. It was occasionally used by soldiers to sleep in, as it was an important military checkpoint. From 2000, primarily wheelchair users and people with mobility impairments resulting from polio started arriving at the abandoned site. It provided a convenient location in the city, in contrast to the camps established for people with disabilities outside of Freetown, which make travel to and from the city centre expensive and time-consuming.

#### 37

The information provided was collected through focus groups led by FEDURP and SLURC in January 2020 as part of the rATA process with HEPPO's residents to document the community's history. In this process they developed a community timeline and prioritised areas for development.

#### 38

Kabia and Tarawally (2017), op. cit.

#### FIGURE 30

Location of the surveys using GPS in Kobo Collect. HEPPO is located in Brookfields, in the city centre of Freetown, next to Pademba Road Prison



The city centre location is important for HEPPO residents as it is both close to the support being given to people with disability, and to desirable places to beg (begging is the chief livelihood of many residents who have suffered from polio). Once the war ended, the soldiers that had been staying on the site left, and additional space became available for more people with disability to move in. Residents started sub-dividing the interior of the building with planks and other makeshift materials. As more people moved in, they occupied the outside spaces of the property, putting up makeshift housing made from corrugated zinc, tarpaulin, sticks, banners and cardboard. Since 2002, the occupants have faced several eviction threats from the military who want to use the space, and the Public Works Department who owned the building before it was destroyed. In 2016, residents in collaboration with BBC Media Action, made a documentary to support their case for secure land tenure.



FIGURE 31
Data collectors from FEDURP conducting the rATA survey in HEPPO during January 2020.
Photo credit: Sulaiman Kamara



Survey respondents by sex in HEPPO

#### 39

FIGURE 32

The identification of individual households in low-income communities in Freetown is difficult due to the unplanned nature of the area and the heterogeneity of family units/types of housing. During the training sessions in December 2019, FEDURP and HEPPO defined a household for the purpose of this survey, as "a group that lives in a room in a separate, individual structure". The criteria of "eating from the same pot" used in Thompson Bay and Dworzark, was discouraged in HEPPO, as it is common that people from different households come together to cook as a coping strategy.

#### FIGURE 33

Survey respondents in HEPPO by age group

#### FIGURE 34

Total population surveyed by age group and sex in HEPPO (number of people)

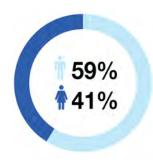
#### **4**0

CODOHSAPA and FEDURP. (2019). Community profiling enumeration report 2019

Freetown, Sierra Leone.

CODOHSAPA-FEDURP. Source

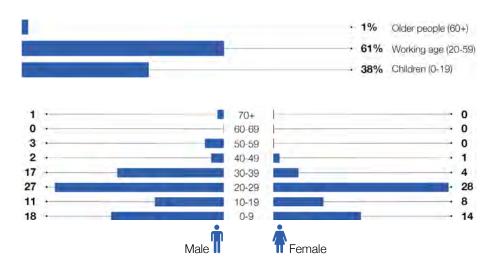
# 1. HEPPO's demographics



The entire community was surveyed, totalling 134 individuals distributed across 54 households.<sup>39</sup> Household composition ranged from one to 14 members. From the total respondents, 41% were women and girls and 59% were men and boys (**Figure 32**). This is different to the findings in Thompson Bay and Dworzark, and other enumerations in low-income communities in Freetown,<sup>40</sup> where there are more females than males in the overall population.

The higher number of men was concentrated in adults over 30: sex was distributed equally until the age of 29 (after 30 there were four times more men than women).

Residents living in HEPPO were very young. Two thirds of the population (61%) were working age adults (aged 20-59) and only 1% of the population was older than 60 years (**Figure 33**). 79% of the population was below 29 years of age, and the largest age bracket was men and women between ages 20-29 (**Figure 34**). Age distribution differed from the findings from the rATA in Thompson Bay and Dworzark in two ways; the population was on average younger in HEPPO, and there were almost no older people (only 1% of the population was older than 60, instead of 4%).

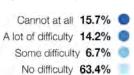


# 2. Disability prevalence and need for AT

# 2.1. Almost half There was a high prevalence of disability in HEPPO (Figure 35)

#### FIGURE 35

Disability prevalence ("some difficulty" and above) in HEPPO





More than a third of the respondents (36.6% or 49 people) have "some difficulty" or more seeing, hearing, walking, remembering or concentrating, self-caring, speaking or communicating. Of these, 29.9% (40 people) have a severe disability, experiencing "a lot of difficulty" and "cannot do at all" in one or more domain. Which means that in HEPPO there are more people (40 people) with a severe disability, than with a milder disability (nine people) (**Figure 37** & **Figure 38**).

As a reference, in Thompson Bay and Dworzark only 4.3% of the population had a severe disability, while in HEPPO it is almost a third of the population (29.9%). In HEPPO, no children had a severe disability.

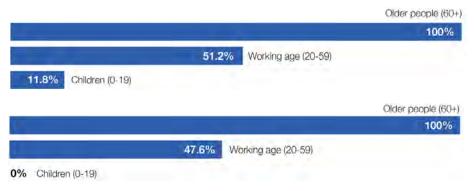
There was a very high prevalence of disability among adults (working age and older people) (Figure 36 & Figure 37): The findings show an age gradient in disability prevalence, 11.8% (six people) of children reported "some difficulty" or above while that figures rises to 51.2% (42 people) in working age people, and to 100% (one person) in older people.

# FIGURE 36

Disability prevalence ("some difficulty" and above) by age group in HEPPO

## FIGURE 37

Severe disability prevalence ("a lot of difficulty" and above) in HEPPO by age group



There is a higher prevalence of disability among males (39.2%) than females (32.7%) (Figure 38 & Figure 39): 39.2% (31 people) of males have a disability, and 32.7% (18 people) of females. Among children, girls have a higher prevalence than boys (girls 18.2% - boys 6.9%), but in the working age population men have higher disability prevalence than women (men 57.1% - women 42.4%). In older people there are only men: there is no woman of older age in HEPPO.

# FIGURE 38 Disability prevalence ("some difficulty" and above) between men and women across age groups in HEPPO

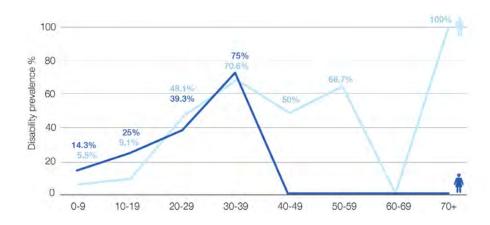
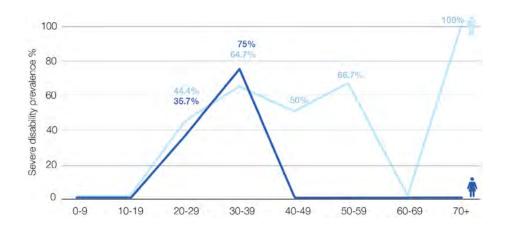


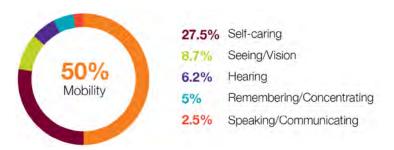
FIGURE 39
Disability prevalence
("a lot of difficulty" and above)
between men and women across
age groups in HEPPO



## 2.2 Mobility was the most common impairment (Figure 40)

Half of the impairments reported are in the domain of mobility (50%), followed by self-caring (27.5%), seeing/vision (8.8%), hearing (6.3%), remembering or concentrating (5.0%) and speaking or communicating (2.5%). There were 80 impairments among the 49 people that reported having a difficulty, indicating that some have difficulties in more than one domain.

FIGURE 40
Distribution of type of impairment amongst people with "some difficulty" and above in HEPPO



**Mobility (50%):** Of the people that have difficulties, half involved moving. Mobility, as the most prevalent impairment, is consistent with HEPPO being a community organized around people affected by polio: most occupants are wheelchair users. Mobility impairment is most prevalent in adults between the ages of 20-59.

**Self-caring (27.5%):** Of the people that have difficulties, almost one third have difficulties with self-caring. As a reference, in Thompson Bay and Dworzark, self-caring had the lowest prevalence reported (5.5%). The fact that a large group has mobility impairments may also be related to them having difficulties getting dressed, bathing and/or going to the toilet (which are all dimensions of self-care). Like mobility, self-caring is more prevalent in adults between the ages 20-59.

**Seeing/vision (8.8%):** Of the people that have difficulties, only 8.8% have difficulties with seeing/vision. As a reference, in Thompson Bay and Dworzark, the prevalence was 35.5%, which is four times more than in HEPPO. Only children (0-9 years old) and younger adults (20-39 years old) reported difficulties in this domain.

**Hearing (6.3%):** Of the people that have difficulties, only 6.3% have difficulties with hearing. It stands out that only young females reported difficulties hearing (five females below 29 years old).

Remembering or concentrating (5.0%) and speaking or communicating (2.5%): These two domains had the lowest prevalence in HEPPO. Like hearing, remembering or concentrating was only present in young females (four females below 29 years old). In terms of speaking or communicating, only two children had difficulties in this domain.

# 2.3. People that have a severe mobility impairment acquired their disability between birth and 15 years old (Figure 41)

The most prevalent impairment in HEPPO, across type of difficulties and domains, is severe mobility impairment (38 people in total have a "lot of difficulties" or above with moving). Due to its prevalence and the small total population, we looked at the age of onset. The most common ages of onset were five (five people) and seven (five people); the average age of onset being six years old. This would be consistent with polio which affects children mostly under the age of five. This shows that most of the people that experience a difficulty in HEPPO are severely disabled with a mobility impairment, and they all acquired their impairments as children.

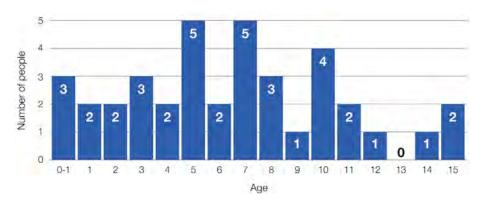


FIGURE 41

Age of onset of people with a severe disability in mobility in HEPPO

# 3. Demand and supply of AT

#### 3.1. AP coverage was relatively high in HEPPO (Figure 42)

71.4% (or 35 people) of the population who need an AP have access to at least one device, which means that 28.6% do not have the AP they need.

People that "cannot do at all" (95.2% or 20 people) and people that have "a lot of difficulties" (78.9% or 15 people) have the best coverage (**Figure 42**): In contrast, people that have "some difficulties" have no AP coverage (0%).

Adults have the best AP coverage (**Figure 43**): The working age population has a coverage of 81%, and older people of 100%. Children across the different levels of difficulties have no AP coverage (0%).

- 0% Some difficulty
- 78.9% A lot of difficulty
- 95.2% Can't do at all
- 71.4% Total

FIGURE 42
AP coverage by difficulty in HEPPO

#### FIGURE 43

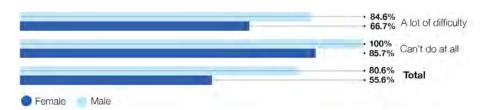
AP coverage by age group in HEPPO



Women and girls have less AP coverage (55.6%) than men and boys (80.6%) (**Figure 44**): Males that "can't do at all" have 100% coverage, while females have 85.7%. Males that have "a lot of difficulty" have 84.6%, while females have 66.7%.

FIGURE 44

AP coverage by sex in HEPPO



## 3.2 Variety of AP was very low (Figure 45)

The survey found 41 devices in total and only four types of AP in use (auxiliary/elbow crutches, wheelchair basic type and push type, and tricycle). This can be compared to the WHO GATE list of priority AP which features 50 products. The most common APs in use were wheelchairs (basic type and push type) (57.6%).<sup>41</sup>

41

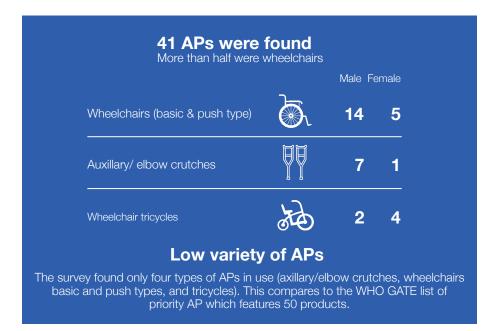
Two further participants stated they had "Other" AP, but the survey did not record what these were. Thus, the extent that these items qualify as assistive products is uncertain and they have not been considered further.

All the APs found related to mobility impairment, these were wheelchairs, crutches and tricycles (**Figure 46**): No APs were found that related to seeing, hearing, communication, remembering and concentrating, and/or self-care; despite there being people with impairments in all these domains. It stands out that no spectacles were found.

There is no significant difference between women's and men's types of AP, both have access to the four types of APs found.

# FIGURE 45

Type of assistive products found by sex in HEPPO





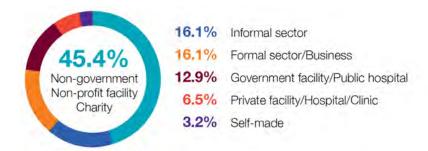
Tricycles in HEPPO.
The rATA survey found six tricycles,
donated by Rokupa Hospital.
The pictures were taken on Kobo
Collect by data collectors.





# 3.3. Almost half of the respondents (45.2% or 14 people) acquired their APs from NGOs/non-profit organizations (Figure 47)

FIGURE 47
Sources of AP owned
by respondents in HEPPO



100% of AT users had a severe disability. In joint second place are the informal sector (16.1% or five people) and private businesses (16.1% or five people). In third place are Government facilities/Public Hospitals (12.9%).

A slightly higher number of people did not pay for their APs (**Figure 48**). All those who sourced their devices from the informal sector paid (100%); whereas AT users who sourced their products from private facilities or made them at home did not pay (100%). People that sourced them from NGOs and non-profit facilities, the largest provider of APs in HEPPO, are split with 42.9% having paid and 57.1% not paying.

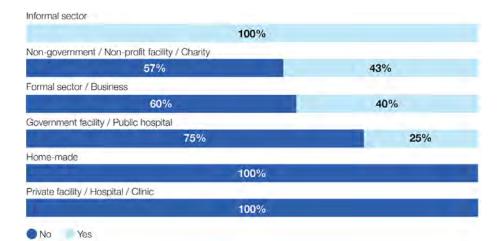


FIGURE 48
Payment of AP by type
of provider in HEPPO

#### 44

# **3.4.** Self-reported AP need was extremely high in HEPPO (Figure 49)

#### FIGURE 49

Self-reported AP Need in HEPPO:

"Do you think you need an AP
you don't currently have?"

even out of ten of the population with

Seven out of ten of the population with an impairment said that they needed an AP that they did not currently have.



73.5% (or 36 people) that experience a difficulty do not have the AP they think they need.

Self-reported AP need is highest among people that have severe disabilities (Figure 50): All individuals who experience "a lot of difficulty" in any one domain (100% or 19 people), and 81% (or 17 people) who are "unable to do" self-reported AP need. This includes people who already have access

to one AP. For example, people that have a wheelchair that stated that they need another AP that could help with mobility and/or with self-caring difficulties.



Self-reported AP need by level of difficulty in HEPPO



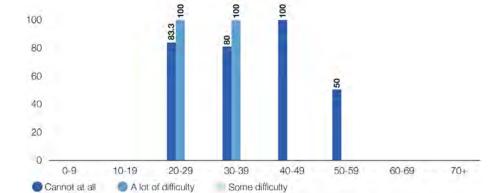
**Self-reported AP need overall is higher in males (74.2%) than females (72.2%) (Figure 51)**: However, within those reporting a severe disability, 100% of females self- reported AP need, while 100% males that have "a lot of difficulty" and 71.4% that "cannot do at all" also self-reported.



#### FIGURE 51

Self-reported AP need by sex in HEPPO

**Self-reported AP need is highest among adults** (Figure 52): Adults 20-39 years old self-reported the most need for AP: 100% of people that experience "a lot of difficulties" in this age range and 80% of the people that "cannot do at all". No one under the age of 19 self-reported the need for AP.

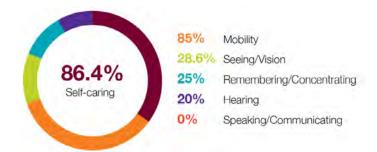


# FIGURE 52 Self-reported AP need by level of difficulty and by age group in HEPPO

## Self-reported AP need is highest in the domain of self-caring (Figure 53):

86.4% (19 people) of people with difficulty in self-caring said that they did not have the AP they need. 85% (34 people) of people with difficulties in the domain of mobility said that they needed an AP. 28.6% (two people) that have difficulties seeing and 25% (one person) with difficulties remembering or concentrating said that they did not have the AP they needed.

FIGURE 53
Self-reported need
of appropriate APs in HEPPO



Affordability is the main reason for not having an AP (91.7%): The most common reason given was "lack of affordability" (91.7% or 33 answers), followed by "not available" (38.8% or 14 answers), "not being aware" (27.8% or ten answers). The least common answer was "lack of transport" and "stigma" (both 2.7% or one answer).

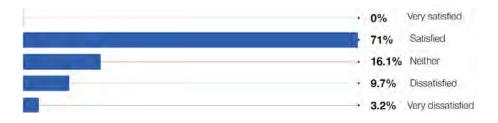
# 4. Satisfaction

Respondents were more satisfied with the maintenance of their APs (scored more frequently as "satisfied") than how suitable or helpful they are (scored more frequently "moderately" satisfied):

Overall satisfaction with the AP (in terms of size, fit, comfort, weight, appearance, safety, and durability) (**Figure 54**): Most respondents (71.0%) were "satisfied" with their products and their services. However, no respondents (0%) were "very satisfied" (the highest score).

FIGURE 54

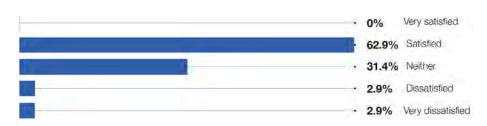
Overall satisfaction with AP in HEPPO: "Over the last month, how satisfied are you with your AP(s)?"



Quality of the service while accessing AP (in terms of procedure, length of time or waiting period, quality of care and attention, and respectful of rights) (**Figure 55**): Most respondents were "satisfied" with their products and their services (female 80.0.%, male 56.0%). However, no respondents were "very satisfied" (the highest score).

#### FIGURE 55

Quality of services while accessing AP in HEPPO: "How satisfied are you with the quality of the service while accessing your AP(s)?"



AP repair, maintenance, and follow-up services (**Figure 56**): Two thirds of AT users (62.9%) were "satisfied" with the maintenance of their AP.

#### FIGURE 56

AP maintenance and follow-up services in HEPPO: "How satisfied are you with repair, maintenance and follow-up services based on your last experience?"



Suitable for the environment (in size, fit, comfort and durability) (**Figure 57**): Two thirds of respondents (68.6%) felt their product was "moderately" suitable to their home and surroundings, indicating a low satisfaction in terms of size, fit, comfort and durability.

#### FIGURE 57

Suitability (in size, fit, comfort and durability) of AP in HEPPO: "Are your AP(s) suitable for your home or surrounding?"



Helpful (allows one to perform everyday activities) (**Figure 58**): Most respondents (87.1%) felt their product was "moderately" helpful for the activities they want to do, indicating a low satisfaction in how the AP allows them to do what they want to do.

#### FIGURE 58

Helpfulness (allows one to perform everyday activities) of AP in HEPPO: "Are you able to what you want to do when using you AP(s)?"



# 5. Recommendations

Recommendations from respondents about how to improve APs in Sierra Leone (Figure 59):

Respondent's answers divided into four types. HEPPO's recommendations were more specific than those given in Thompson Bay and Dworzark, which could be explained by the high number of people with disabilities and AT users.

A larger role for the government in improving access and affordability of the devices and their maintenance: "Government should try to make the AT products more comfortable and affordable for us"; "Help from the government to provide us with ATs"; "Government should help us by providing a wheelchair that is electronic."

**More private businesses selling AT products:** "We need shops that deal with AT products"; "Business enterprises should invest in AT products"; "Available everywhere and at a reasonable cost."

**Improve the comfort of AP:** "This one is painful when using it continuously, we need an improved version, and it should be available everywhere."

**NGOs delivering more AT:** "Honestly, we need more NGOs and charitable organizations to come to our aid to support us get access to ATs."

"Government should try to make the AT products more comfortable and affordable for us"

#### FIGURE 59

Recommendations from respondents about how to improve AP in Sierra Leone, open-ended answers

<sup>&</sup>quot;More NGOs and charitable organizations to come to our aid to support us get access to ATs"

<sup>&</sup>quot;Business enterprises should invest in AT products, available everywhere and at a reasonable cost"

<sup>&</sup>quot;This one is painful when using it continuously, we need an improved version, and should be available everywhere"

# Key findings from the rata survey in HEPPO

**The population in HEPPO was very young:** 79% of the respondents were under the age of 29, a large proportion of whom were male.

There was an extremely high prevalence of severely disabled adults with mobility impairments: More than a third of the population (36.6%) had a disability. Very few people (nine) reported having "some difficulty" in a domain, so most related to severe disability (29.9%). It stands out that half of the adults in HEPPO had a severe disability (47.6%) and most of these were in the domains of mobility (50%) and self-caring (27.5%).

All the respondents that acquired a severe mobility disability acquired it as a child, on average (median) at the age of six. This is in line with HEPPO being a community organised mainly by wheelchairs users who suffered from polio (a disease that affects children under five). The low prevalence of difficulties in the domain of seeing/vision also stands out, with only 8.8% of the population reporting such difficulties (this is four times less than in Thompson Bay and Dworzark, where the prevalence was 35.3%). No spectacles were found in HEPPO, as opposed to Thompson Bay and Dworzark, where this was the most common AP.

Males have a higher disability prevalence, but females have significantly less AP coverage: Men have a slightly higher disability prevalence than females (males 39.2% - females 32.7%). This is opposed to the findings from Thompson Bay and Dworzark, where females had a higher disability prevalence than males (females 21.6% - males 19.5%). However, while males had significantly better AP coverage than females (Males 80.6% - females 55.6%), there was no difference in the type of AP they used. Males and females had access to the same four types of AP (manual wheelchairs push and basic types, crutches and tricycles). In Thompson Bay and Dworzark, females also had significantly less AP coverage, but also only had access to less sophisticated APs.

Disability prevalence in children was low, however girls had high prevalence in less common impairments: The disability prevalence in children was low (11.8%), even lower than in Thompson Bay and Dworzark (13.5%). As opposed to adults, there were no severely disabled children in HEPPO. Unlike Thompson Bay and Dworzark, girls had a higher prevalence than boys (girls 18.2% - boys 6.9%). It stands out that only young females (under 20 years old) reported having difficulties hearing (five females) and in remembering or concentrating (four females).

49 I

AP coverage was high, but satisfaction with devices was "moderate" and self-reported need for AP was extremely high: 71.4% of the disabled population had access to at least one device. This was particularly high in those with a severe disability (95.2% in "cannot do at all" and 78.9% in "a lot of difficulty"). However, the variety of devices in use was very low: only four different types of AP were found (wheelchairs basic and push type, crutches, and tricycles). All the devices related to a mobility impairment. It stands out that no spectacles were found.

Although AP coverage was high, satisfaction with current devices was relatively low (68.6% reported that the device was "moderately" suitable for their environment and 87.1% that it was "moderately" helpful for everyday activities). Self-reported need for AP was extremely high (73.5%). The highest self-reported need for AP concerned self- caring (86.4%) followed by mobility (85%). This means that although many people have an assistive device, they reported needing others and/or an improved version of what they have. Most respondents said that they do not have the AP they need because of lack of affordability (91.7%).

The high AP coverage contrasts starkly with the low coverage found in Thompson Bay and Dworzark, where only 14.9% of the population in need had an AP. It also differs in terms of coverage for those with the most difficulties. While HEPPO had very high coverage for those that "cannot do at all" (95.2%), in Thompson Bay and Dworzark, this was not the group that had the highest coverage (only 22.2%, and those with "a lot of difficulties" had the best coverage of 35.4%).

Most of the APs in HEPPO come from non-governmental organizations: Including non- profit facilities/charity organizations (45.4%), followed by the informal sector (16.1%). 42.9% of the people who sourced their AP from NGOs and non-profit facilities paid for their device, and 57.1% did not. All people who sourced their device from the informal sector paid (100%), whereas the AT users who sourced their products from private facilities or made them at home did not pay (100%).

These findings are very different to those in Thompson Bay and Dworzark, where most of the respondents paid for the AP (70.7%). This could be because most of the AP were spectacles bought in the informal sector, whilst in HEPPO most of the APs found were wheelchairs and tricycles provided by NGOs.

# **CHAPTER 5**

Kelayan Barat & Pelambuan, Indonesia

# Kelayan Barat and Pelambuan, Indonesia

#### 42

Indonesia National Bureau of Statistics (BPS) (2020). Percentage of Urban Population by Province, 2010- 2035. BPS. bps.go.id/statictable/2014/02/18/1276/ persentase-penduduk-daerah-perkotaanhasil-proyeksi-penduduk-menurut-provinsi-2015---2035.html

#### 43

For example, according to SUPAS 2015 (the 'In-between Census Survey') the number of people with disability in Indonesia is 21.8 million, equivalent to 8.6% of the total population. Source

#### 44

Indonesia National Bureau of Statistics (BPS) (SUSENAS) (2012). National Social-Economic Survey 2012. BPS.

<u>Source</u>

#### 45

Walker et al. (2020 a), op. cit.

#### 46

Clinton Health Access Initiative (CHAI) (2019). Assistive Technology Country Capacity Assessment Indonesia. CHAI.

Source

#### 47

Walker et al. (2020 a), op. cit.

# Context

#### Disability and Assistive Technology in Indonesia

The Indonesian population is 265 million, with 56% living in urban areas and 44% in rural areas. 42 It has been estimated that between 4% and 11% of the Indonesian population is affected by a disability. 43 It is estimated that 60% of these disabilities are caused by diseases and 16% by accidents. 44 This wide range in the prevalence rate arises from different national surveys defining and measuring disability in the country. Disabled People's Organizations, however, have maintained that these figures are still low, and have started initiatives to collect more accurate, specific data on disability. 45

Indonesia has ratified the Convention on the Rights of Persons with Disabilities through Law 19/2011 and followed it up with Law 8/2016 on Persons with Disabilities, which encompasses the fulfilment of AT. Until 2019, the coverage of AT in the country was still low, affecting only 0.1% of the total number of people with disabilities. Although several systems of data collection, planning, and budgeting for AT in Indonesia are in place, they have not yet been integrated nationally.

As DPU-UCL 's previous research showed, some of the main providers of ATs are non-state actors, and databases often do not list these providers. <sup>47</sup> There are several factors that have impeded access to AT in Indonesia. Some issues include the complex bureaucratic system among regional and national governments in financing affordable AT, and the high discrepancy between demand and availability that has resulted in unaffordable prices. These factors have resulted in people with disability in Indonesia having insufficient access to basic AT such as eyeglasses, hearing aids, wheelchairs, and mobile applications.



Residents washing clothes in the river, in a Pelambuan informal settlement.

Photo credit: Kota Kita

#### **Pelambuan community**

48

Indonesia National Bureau of Statistics (BPS) (2020), op. cit.

49

Kota Kita (2018). Banjarmasin City: A Disability-Inclusive City profile. Kota Kita. Source Pelambuan is located in the west of Banjarmasin with a total population of 30,827, 51.4% male, and 49.6% female.<sup>48</sup> The population density in the neighbourhood is around 14, 541.04 persons/km² with a total of 1,813 households. Historically, Pelambuan was an industrial area for rubber that Dutch companies previously owned as it is strategically located near the port. This attracted factory workers. Today, the Pelambuan neighbourhood includes four RW (unified blocks) consisting of 72 RT (blocks) spread structurally across the area.

The majority of Pelambuan 's population is Muslim (98.1%) followed by small number of Protestant (1.72%), Catholic (0.12%), and Hindu (0.1%) people respectively. Approximately 79.4% people in the age range 10-64 years never attended school, and 22% only attended primary school. In terms of workforce, 20% of the Pelambuan population is unemployed, while 17.3% work in manual labour.

Based on Kota Kita's research on disability in Banjarmasin,<sup>49</sup> the disability prevalence in the neighbourhood can be explained by the absence of safe pedestrian infrastructure combined with heavy truck access to and from the port. Many residents, especially people with disabilities, are left vulnerable to traffic accidents. The neighbourhood is associated with industry, chiefly timber and rubber. 12% of disabilities in Pelambuan are caused by traffic accidents and work hazards, and those affected continue residing in the neighbourhood because of the existing social support system. This can explain the higher level of disability in the neighbourhood.

### Kelayan Barat

Kelayan Barat is located in the southern part of Banjarmasin. Kelayan Barat is categorised as a slum area based on the assessment of the Kotaku programme with the Government of Banjarmasin. The population in Kelayan Barat reached 6,754 people in 2020, 50% male and 50% female. The population density in the neighbourhood is around 23,289.66 persons/km2. Meanwhile, the number of households registered to the government is 1,769 spread over 15 RTs (blocks) and one RW (unified block). Historically, Kelayan Barat was known for its rice granary and commercial area, which sits along the Muara Kelayan riverside. The establishment of the Ujung Murung Market (currently known as Lima Market) around 1900 and new settlements have congested the Muara Kelayan area, which has become part of the administrative district of Kelayan Barat neighbourhood.

The majority of Kelayan Barat 's population is Muslim (94.3%) followed by Catholic (3.3%), Buddhist (1.35%), and Protestant (1.05%). Regarding education, 27% of the population in Kelayan Barat completed high school. However, 25% of the population aged 18-56 years and above received no formal education: 11% never had the opportunity to access education, and 14% did not finish primary education.



### FIGURE 60

Location of Pelambuan and Kelayan Barat using GPS from Kobo Collect. Pelambuan (to the left) is located on the west side of the city on the Borito River, while Kelayan Barat (to the right) is located in the south part of Banjarmasin, on the Muara Kelayan riverside.

# Kelayan Barat and Pelambuan's demographics

#### FIGURE 61

Survey respondents by sex in Pelambuan and Kelayan Barat

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In Indonesia, Kota Kita identified households first through the Family Card from the Civil Registry Office (or Kartu Keluarga from the Dinas Kependudukan dan Catatan Sipil) and these were then updated on the ground by data collectors. For the purpose of this survey, the new households identified were defined as "a family group that cooks/eats together".

Data collector from Kaki Kota conducting the survey in Banjarmasin. Photo credit: Kota Kita



The 2,046 individuals surveyed were distributed across 833 households.<sup>50</sup> Household composition ranged from one person to ten, and the average number of household members was four. Of the total respondents, the sex distribution was split evenly between females (49.6%) and men (50.4%) (**Figure 61**). The population was distributed across ages, with more than half (59%) of the population in the working age group (20-59 years old).



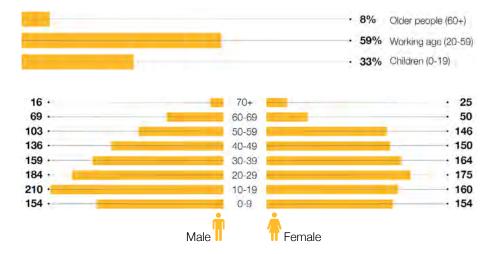
The average age of the respondents was 31 years. Only 8% of the population was older than 60 years (**Figure 62**). Boys (10-19) make up the largest group (210) (**Figure 63**).

#### FIGURE 62

Survey respondents by age in Kelayan Barat and Pelambuan

## FIGURE 63

Total population surveyed by age group and sex in Kelayan Barat and Pelambuan



# 2. Disability Prevalence and need for AT

# 2.1. There was a high prevalence of disability in the two communities (Figure 64)

30.9% (633 people) of the respondents have "some difficulty" or greater seeing, hearing, walking, remembering or concentrating, self-caring, speaking or communicating. Of these, 7.0% (144 people) have a severe disability, experiencing "a lot of difficulty" and "cannot do at all" in one or more domain.

FIGURE 64

Disability prevalence ("some difficulty" and above) in Kelayan Barat and Pelambuan



There is a higher prevalence of disability among older people than in children and the working age population (Figure 65): The findings show an age gradient in disability prevalence. 8.7% of children reported "some difficulty" or above, while that figure rises to 38.4% in working age people and to 69.4% in older people.

#### FIGURE 65

Disability prevalence ("some difficulty" and above) by age group in Kelayan Barat and Pelambuan



There is a higher prevalence of disability among girls and women (34.9%) than in their male counterparts (27.1%) (Figure 66): 34.9% of females (354 people) have a disability, as opposed to 27.1% (279 people) males. This is also the case for severe disability, where 8.1% females and 6.0% males declared having "a lot of difficulty" and above in any one domain. Although females have a higher overall disability prevalence, older men have a higher disability prevalence than women, both in general prevalence of disability (81.3% males and 76% females) and in severe disability (49.9% males and 36% females) (Figure 67 & Figure 68). There is no significant difference in the disability prevalence of Pelambuan (30.3%) and Kelayan Barat (31.6%).

## FIGURE 66

Disability prevalence by sex in Kelayan Barat and Pelambuan

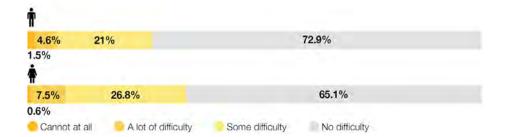


FIGURE 67
Disability prevalence
("some difficulty" and above) between
men and women across age groups in
Kelayan Barat and Pelambuan

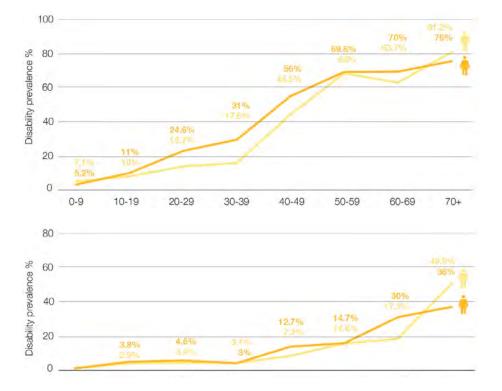


FIGURE 68
Disability prevalence

("a lot of difficulty" and above) between men and women across age groups in Kelayan Barat and Pelambuan

### 2.2. Seeing/vision was the most common impairment (Figure 69)

Half of the impairments reported were in the domain of seeing/vision (54.7%), followed by mobility (18.7%) and remembering or concentrating (10.2%). There were 934 impariments amongst the 633 people that reported having a difficulty, indicating that some people have difficulties in more than one domain.

#### FIGURE 69

Distribution of type of impairment amongst people experiencing "some difficulty" and above in Kelayan Barat and Pelambuan



**Seeing/vision (54.7%)**: Of the people that have difficulties, half involve seeing/vision. Difficulty in seeing increases consistently with age, both in men and women, with a sharper increase over the age of 50. Men between 50-59 years old (64.1%) and women between 60-69 years old (64.0%) have the most difficulty in seeing/vision.

**Mobility (18.7%):** Of the people that have difficulties, 18.7% have difficulty moving. Like vision, mobility difficulties increase consistently with age, both in men and women, with a sharp increase in people over 70. Six out of ten men have "some difficulty" or more moving (62.2%), and five out of ten women (56%) in this age bracket.

**Remembering or concentrating (10.2%):** Women tend to have a higher prevalence of difficulties related to remembering or concentrating: this is particularly significant over the age of 60. For example, 40% of women over 70 years old have difficulty remembering or concentrating. This is three times greater than their male counterparts (12.5%).

**Hearing (8.4%):** Hearing difficulties are the fourth most present impairment: 8.4% impairments relate to a hearing difficulty. As with the other domains, prevalence increases with age, particularly over 60 years. The highest prevalence exists within women over 70, in which one out of three has difficulty hearing (32%), while men tend to have lower difficulty (18.8%).

**Self-caring (4.8%) and speaking or communicating (3.3%):** Although the prevalence of these two domains is the lowest overall, they increase drastically with age. Speaking or communicating difficulties are most prominent in men and women over 70. For example, one out of five women has a difficulty speaking or communicating (20%). Similarly, difficulties in self-caring are six times more prominent in people over 70 than the average across the population. One out of three men (31.3%) and women (28%) have difficulty eating, getting dressed, bathing or going to the toilet on their own. This contrasts to 0-1.5% in younger adults (20 to 50 year olds).

# 2.3. Most respondents acquired their severe disabilty as adults, on average (median) between the ages of 40 and 61 years (Table 4)

The impairments acquired at the youngest age were difficulty seeing (40 years old) and difficulty remembering or concentrating (48 years old). These are followed by difficulty hearing (57 years old), difficulty speaking or communicating (58 years old), mobility difficulties (58 years old), and self-caring (61 years old). Seeing, the most common severe disability (107 people), is the one acquired at the youngest age.

**TABLE 4**Age of onset in Kelayan Barat and Pelambuan

Severe disability ("a lot of difficulty" and more)	Age of onset (Median)	Number of people
Seeing / Vision	40	107
Remembering / Concentrating	48	17
Hearing	57	21
Speaking / Communicating	58	8
Mobility	58	41
Self-caring	61	12

# 3. Demand and Supply for AT

### 3.1. AP coverage is low in the two communities (Figure 70)

Almost half of the population (47.4%) that have a difficulty has at least one device they need, while 52.6% do not have any AP.

**Respondents with "some difficulty" have the least AP coverage**: The group that has the greatest AP coverage is those with "a lot of difficulties" (69.9% AP coverage), while the group with the least coverage is those that have "some difficulties" (41.3% AP coverage). It is worth highlighting that respondents that "cannot do at all" are less likely to have AP that those with a "lot of difficulty" (**Figure 71**).

#### FIGURE 70

AP coverage by difficulty in Kelayan Barat and Pelambuan



**Children have the lowest AP coverage (30.5%)**: while older people have the highest AP coverage (55.9%). However, this number is still low (**Figure 71**).

#### FIGURE 71

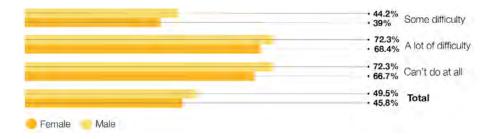
AP coverage by age group in Kelayan Barat and Pelambuan



Women and girls have less AP coverage (45.8%%) than men and boys (49.5%) (Figure 72).

#### FIGURE 72

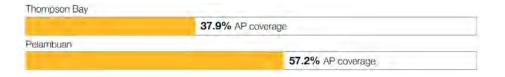
AP coverage by sex in Pelambuan and Kelayan Barat



Respondents in Pelambuan have better AP coverage (57.2%) than those in Thompson Bay (37.9%) (Figure 73).

#### FIGURE 73

AP coverage by neighbourhood



## **3.2.** The variety of AP in use is low (Figure 74)

The survey found only eight types of APs in use listed on the WHO GATE list (which features 50 products). There were three "Other APs" mentioned that are not featured on the list: inhaler, nebulizer and "Softlance" diabetes injector kit.

The total AP found in the two communities was 308 devices, 93.8% were spectacles: The AP divided in the following way: 289 spectacles, one manual wheelchair (push type), two manual wheelchairs (basic type), two white canes, five canes/sticks, tripod and/or quadripod, two orthosis, two therapeutic footwear and two nebulizers. The following devices were listed by one participant each: inhaler, magnifiers (optical/digital, including telescope), and 'Softlance' diabetes injector kit.

All the APs found related to mobility or seeing: No APs were found that related to hearing, communication, remembering and concentrating, and/or self-caring despite there being people that have impairments in all of these domains. For seeing, 99% of the devices were spectacles and the remaining 1% consists of one magnifier, optical/digital (including telescope) and two white canes. For mobility, the devices were spread more evenly between manual wheelchair (push type and basic type), orthosis, therapeutic footwear, canes/sticks, tripod and quadripod.

93.8% Spectacles	60	136	153
Cane/sticks, tripods,quadripods		3	4
Wheelchairs (basic & push type)		1	2
Auxillary/ elbow crutches	PP	1	2
Rollator/Walking Frame	Á	1	0
Therapeutic footwear		0	2
		1	1
Nebulizer		0	1

# FIGURE 74 Type of assistive products found by sex in Kelayan Barat and Pelambuan

#### 60

# **3.3.** The informal sector was the largest source of AP (Figure 75):

Two thirds (65.3%) of respondents obtained their AP, mostly spectacles, from the informal sector defined as shops or enterprises that are not legally registered as AT providers. This is followed by formal private sector businesses (24.4%). Data collectors defined "informal providers" as shops or enterprises that are not legally registered as AT providers.

#### FIGURE 75

Sources of AP owned by respondents in Kelayan Barat and Pelambuan



Most AT users paid for their AP (**Figure 76**): Except for APs provided by NGOs, where only one third of respondents (33.3%) paid for their AP.

## FIGURE 76

Payment of AP by type of provider in Kelayan Barat and Pelambuan



# 3.4. Almost a fifth of the people that experience a difficulty do not currently have the AP they think they need (17.5% or 117 people (Figure 77)

## FIGURE 77

Self-reported AP need in Kelayan Barat and Pelambuan: "Do you think you need an AP you don't currently have?"



Self-reported AP need is higher in people that have a severe disability (Figure 78): Half of the respondents (52.4%) that "cannot do at all" in any one domain said that they need an AP that they currently do not have. While respondents with the least difficulties ("some difficulty") reported the least need for AP (12.3%).

#### FIGURE 78

Self-reported AP need by level of difficulty in Kelayan Barat and Pelambuan



**Self-reported AP need is slightly higher in females (17.8%) than males (17.2%)** (Figure 79): Females self-reported higher AP need than males amongst people with "some difficulty" (Female 31%-Male 25.4%) and "a lot of difficulty" (Female 80.9%-Male 80%).

12% Some difficulty
12.5% Some difficulty
27.7% A lot of difficulty
35.5% A lot of difficulty
60% Can't do at all
17.2% Total
17.8% Total

FIGURE 79
Self-reported AP need by sex in
Kelayan Barat and Pelambuan

**Self-reported AP need is similar across ages** (Figure 80): Except for respondents aged 30 to 39 who "cannot do at all". This type of difficulty is the clearest indicator of need of AP. Respondents with severe disabilities across all age groups and sexes self- reported the most unmet need.

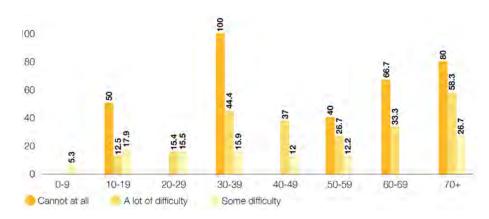


FIGURE 80

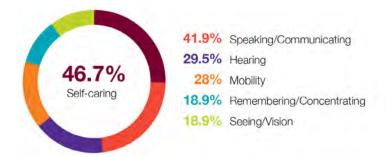
Percentage of unmet need by level of difficulty and by age group in Kelayan Barat and Pelambuan

**Self-reported AP need is highest in people that have difficulty in self-caring** (Figure 81): Almost half of the respondents (46.7% or 21 people) that have difficulty in self-caring self-reported the need for an AP. This is followed by speaking and communicating (41.9% or 13 people), and hearing (29.5% or 23 people). The impairment that respondents self-reported the least need for AP for was in seeing/vision (18.6% or 95 people).

Affordability is the main reason for not having an AP (53.8%): Of the 117 individuals who self-reported AP need, the most common reason given was lack of affordability (53.8% or 63 answers), followed by "not being aware" (15% or 18 answers), and "not suitable" (8.0% or nine answers). The least common answer was "lack of transport" (no answers for this option).



Self-reported need for appropriate APs for specific difficulties in Kelayan Barat and Pelambuan



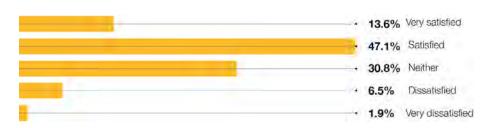
# 4. Satisfaction

Respondents were generally more satisfied with the quality of their AP than the maintenance and follow-up services.

**Overall satisfaction with the AP** (in terms of size, fit, comfort, weight, appearance, safety, and durability) (**Figure 82**): 60.7% of respondents were "satisfied" or "very satisfied" with AP quality and only 1.9% were very dissatisfied.

# FIGURE 82

Overall satisfaction with AP in Kelayan Barat and Pelambuan: "Over the last month, how satisfied are you with your AP(s)?"



**Quality of the service while accessing AP** (in terms of procedure, length of time or waiting period, quality of care and attention, and respectful of rights) (**Figure 83**): More than a third of respondents were "satisfied" (41.9%), while a similar proportion were "neither satisfied nor dissatisfied" (42.2%).

#### FIGURE 83

Quality of services while accessing AP in Kelayan Barat and Pelambuan: "How satisfied are you with the quality of the service while accessing your AP(s)?"



**AP repair, maintenance, and follow-up services** (Figure 84): More than a third of respondents were "satisfied" with the maintenance of their product (39.4%).

#### FIGURE 84

AP maintenance and follow-up services in Kelayan Barat and Pelambuan: "How satisfied are you with repair, maintenance and follow-up services based on your last experience?"



#### Suitable for the environment (in size, fit, comfort and durability)

(**Figure 85**): Two thirds of respondents felt their product was "moderately" suitable to the home and surroundings (65.6% or 202 people), and only 2.6% felt it was "completely" suitable.

#### FIGURE 85

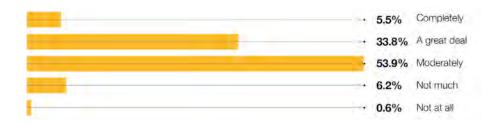
Suitability (in size, fit, comfort and durability) of AP in Kelayan Barat and Pelambuan: "Are your AP(s) suitable for your home or surrounding?"



Helpful (allows to do the everyday activities) (Figure 86): Half of respondents felt their product was "moderately" helpful (53.9% or 166 people), and only 5.5% felt it was "completely" suitable.

#### FIGURE 86

Helpfulness (allows to do everyday activities) of AP in Kelayan Barat and Pelambuan: "Are you able to what you want to do when using you AP(s)?"



#### 5. Recommendations

Recommendations from respondents about how to improve APs in Indonesia (Figure 87): Respondents' answers are divided into four recommendations:

- 1. Improve affordability "AT should be provided free of charge, especially for people who can't afford it", "The provision of assistive devices to people with disabilities must really reach people who really need them and at no cost", "It's not affordable".
- 2. Increase awareness in the government about importance of AP "AP should be a priority for the government"
- 3. Improve the access of APs through the BPJS system
- "Although you can access some AT through BPJS51 it is still complicated, and the waiting list is long".
- 4. More information about APs and how to get them

"I don't know where to take my complaints about AT"

### FIGURE 87

Recommendations from respondents about how to improve AP in Indonesia, open- ended answers

The BPJS is the state subsidized health insurance system.

"I don't know where to complain about my AP"

"APs are not affordable"

"AP should be a priority for the government"

"Although you can access some AT through BPJS<sup>51</sup> it is still complicated, and the waiting list is long"

#### 64

# Key findings from the rata survey in Pelambuan and Kelayan Barat, Indonesia

The population in Pelambuan and Kelayan Barat was distributed fairly evenly across ages, and the average age of respondents was 31 years old: More than half (59%) of the population was in the working age bracket (20-59 years old). Boys (10-19 years old) made up the largest group.

One third (30.9%) of the population had a disability and 7.0% had a severe disability. Seeing was the most common impairment: From the respondents that reported having a difficulty, more than half (54.7%) had difficulties in seeing/vision and one fifth (18.7%) had difficulties in mobility. Most people who had a severe disability acquired it as an adult. Difficulty in seeing/vision was acquired on average at the age of 40 years, and had a very high prevalence in older people. Men between 50-59 years old (64.1%) and women between 60-69 years old (64.0%) had the most difficulty in the domain of seeing/vision. This level of disability prevalence is strikingly different from the prevalence of between 4% to 11% from the national surveys, cited earlier in this report.

There was a higher prevalence of disability among older people, but they had the best AP coverage: There was a high prevalence of disability in older people. 69.4% of people over 60 had a disability, which was much higher than the working age population (38.4%). Women between 60-69 years old (64.0%) had the most difficulty in seeing/vision. Six out of ten men over 70 had difficulty moving (62.2%). Respondents over 60 years old had the best AP coverage (55.9%), although this coverage still only covered half of the population in need.

Females had higher disability prevalence than males and had less AP coverage: 34.9% of females had a disability, as opposed to 27.1% of males. This is also the case for severe disability (female 8.1% - male 6.0%). Females had less AP coverage (male 49.5% - female 45.8%), however they owned more varied APs than males. Females had seven types of APs (spectacles, push and basic type of wheelchair, white canes and canes/sticks, orthosis, therapeutic footwear, tripod and/or quadripod), while men only had four types (spectacles, basic type of wheelchair, orthosis and canes/sticks, tripod, quadripod). There was no significant difference between the self-reported AP need between females (17.8%) and males (17.2%)

**AP coverage was low and the variety was limited:** Almost half of the population (47.4%) that had a difficulty had access to at least one device they needed, while 52.6% did not have any AP. Respondents that had "some difficulty" had the least AP coverage (41.3% AP coverage), while the group that had the most AP coverage was those with "a lot of difficulties" (69.9% AP coverage).

The variety of devices was very low, and the survey only found eight different types of APs and most of them were spectacles (93.8%). All the devices related to a mobility and seeing/vision impairment, despite there being people that had impairments in all the domains. Self-reported AP need was highest among respondents that have difficulties in self-caring. 46.7% that had difficulty in self-caring self-reported the need for an AP, followed by speaking and communicating (41.9%) and hearing (29.5%). The impairment in which respondents self-reported the least need for AP was in seeing/vision (18.6%). The most common reason (53.8%) given for not having the AP they needed was affordability, followed by not being aware (15%).

Most of the APs owned in Kelayan Barat and Dworzark came from the informal market: Two thirds (65.3%) of the respondents obtained their AP, mostly spectacles, from the informal sector, defined 'informal providers' as shops or enterprises that are not legally registered as AT providers, followed by the formal private sector businesses (24.4%). Respondents were generally more satisfied with the quality of their AP than the maintenance and follow-up services.

# CHAPTER 6

Overall Findings

# **Overall findings**

The findings of each case study have been presented separately in the previous chapters as they relate to each specific context. However, it is also possible to identify some common findings across case studies. While future, larger studies are needed in low-income, urban settlements to confirm these patterns, the data from the three rATA surveys conducted in Indonesia and Sierra Leone showed the following:

# Self-reported disability prevalence ("some difficulty" and above) and severe disability ("a lot of difficulty" and above) is high in the four 'mainstream' communities

52

Disability measures vary depending on the methods used. The World Health Survey and Global Burden of Disease, respectively, referred to in the World Report on Disability (2011), op. cit. 20.6% and 4.3% of the population in Sierra Leone; 30.9% and 7.0% of the population in Indonesia; and 36.6% and 29.9% (extremely high) in HEPPO. As a reference, international figures indicate that global disability prevalence is 15.6%-19.4% and severe disability is 2.2%-3.8%. <sup>52</sup> This shows that disability is a widely spread issue and should be integrated when planning interventions into these low-income urban communities (**Figure 88**).

#### FIGURE 88

Disability prevalence in the three case studies

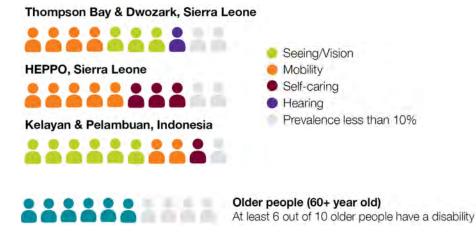


The findings also justify the implementation of the rATA, as a rapid data collection tool, as it provides new figures on disability prevalence in these case studies. In all the cases, the self-reported disability prevalence from the rATA is much higher than that stated in each country's population survey. In Sierra Leone, the 2015 Population and Housing Census registered 1.3% disability prevalence, compared to 4.3% from the rATA. In Indonesia, national surveys estimate disability prevalence between 4% and 11%, which is also strikingly different to the 7% from the rATA. These measures of disability will vary depending on the methods used (the national surveys in both countries do not use the Washington Group Short Set of Questions).

Although the rATA does not replace clinical assessments of functional impairment, it provides a rapid and low-cost tool which uses consistent and comparable survey elements, and brings in AT users' own perspectives and experiences. This has helped raise awareness about disability and the need for AT in this context. For example, in Indonesia, as mentioned in Chapter 5, DPOs have claimed that the national figures are low, and have started initiatives to collect more consistent and comparable data on disability, for which the rATA could be one of the methods used.

# 2. The most common impairments reported by participants regard mobility and seeing/vision

The least common impairments are speaking or communicating, and remembering or concentrating, but their presence rises significantly in older people. Considering how impairments distribute across age and sex can help to target interventions (**Figure 90**).



#### FIGURE 89

Most common impairments in the three case studies

#### FIGURE 90

Disability prevalence in older people in the three case studies

# 3. More than half of the older population have a disability

(62.5% in Thompson Bay and Dworzark, Sierra Leone; 69.4% in Kelayan and Pelambuan, Indonesia; and 100% in HEPPO) and most are severely disabled. This is higher than the international figures which state that 50% of older people have disabilities. The age of onset in mainstream communities occurs in adulthood, indicating that the environment plays an important role in disability prevalence. The World Disability Report states that "higher disability rates among older people reflect an accumulation of health risks across a lifespan of disease, injury, and chronic illness" indicating that "the environment has a huge effect on the prevalence and extent of disability, and on the disadvantage faced by persons with disabilities." In both countries, the national data referred to in each case study indicated that diseases and accidents were the most common cause of disability, and thus interventions that address these areas could help prevent disabilities and slow their progress towards a more severe disability.

53
World Report on Disability (2011),
op.cit.

54

Pages 35 and 44, respectively.

#### 55

For example, there is a recent study showing that women with disability are more likely to be excluded from digital ATs. GSMA (2020). The Digital Exclusion of Women with Disabilities. Source

# 4. The findings suggest that there could be a relationship between sex and disability prevalence/access to AT<sup>55</sup>

Females tended to have slightly higher disability prevalence than males, less AP coverage and more self-reported AP need (**Figure 95**). In the case of Thompson Bay and Dworzark (Sierra Leone), females also had less sophisticated APs than males.

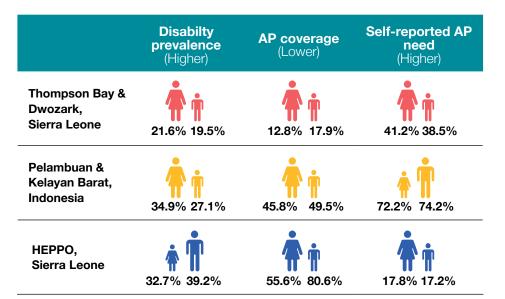


FIGURE 91
Relationship between sex and key indicators in rATA

# 5. AP coverage in mainstream communities is low among the population in need

14.9% in Thompson Bay and Dworzark, Sierra Leone and 47.4% in Kelayan Barat and Pelambuan, Indonesia. In contrast, self-reported AP need was high in all the case studies (40.1% Thompson Bay and Dworzark, Sierra Leone; 17.5% Kelayan Barat and Pelambuan, Indonesia; and 73.5% HEPPO). Severely disabled respondents ("a lot of difficulty" and above) had better AP coverage than people with "some difficulty" and above. However, it is worth highlighting that those reporting "a lot of difficulty" had better AT access than respondents that "cannot do at all"; and that those who "cannot do at all" reported higher AT need. Severely disabled respondents also self-reported the most need for AP (across age groups and sex), indicating that the AP they currently have does not cover all their needs and/or they need a further device for other impairments. They are thus a key group to focus on.

## AP variety is extremely low

From more than 4,000 respondents across five case sites in two countries, there were only ten types of devices identified, compared with the WHO GATE list of priority AP which features 50 products. Furthermore, the APs found were related to only mobility and seeing/vision. The most common AP was spectacles which accounted for most of the devices found (81.0% in Thompson Bay and Dworzark, Sierra Leone; and 93.8% in Kelayan Barat and Pelambuan, Indonesia) (Table 5).

**Tricycle** 

Therapeutic Footwear

**Orthosis** 

HEPPO,

Sierra Leone

Mobility

Mobility

Mobility

Assistive Products	Domain	Thompson Bay and Dworzark, Sierra Leone	Kelayan and Pelambuan, Indonesia	HEPPO, Sierra Leone
Spectacles	Seeing/vision	52	289	0
Auxiliary/elbow crutches	Mobility	3	0	8
Canes/sticks, tripod, quadripod	Mobility	1	5	0
Manual wheelchair (basic type)	Mobility	2	2	13
Manual wheelchair (push type)	Mobility	1	1	6
Rollators and walking frame	Mobility	1	0	0
White canes	Seeing/vision	0	2	0

**TABLE 5**Total APs found in the general population in the three cases

Self-caring devices were a priority in all the case studies, and more than half of
the respondents that had a difficulty in self-caring said that they did not have the
AP they needed (52.9% Thompson Bay and Dworzark, Sierra Leone; 46.7%
Kelayan Barat and Pelambuan, Indonesia; and 87% HEPPO). Seeing/vision de-
vices were a priority in Thompson Bay and Dworzark, Sierra Leone (56.6%),
and speaking or communicating devices (41.9%) were a priority in Kelayan and
Pelambuan, Indonesia ( <b>Table 6</b> ).

0

1

0

0

2

2

6

0

0

Seeing (29%)

**Domain** 1st 2nd 3rd **Thompson Bay** and Dworzark, Vision (57%) Self-caring (52%) Hearing (52%) Sierra Leone Kelayan and Speaking and Pelambuan, Self-caring (47%) communicating Hearing (30%) Indonesia (42%)

Mobility (85%)

Self-caring (86%)

TABLE 6
Self-reported need of appropriate
APs by order of priority in
the three case studies

# 7. Most people get their AP from the informal market

1 30.8% in Thompson Bay and Dworzark, Sierra Leone; 65.3% Kelayan and Pelambuan, Indonesia. However, it is important to consider that most of these devices were spectacles. In the case of HEPPO, where the most common AP was wheelchairs, these came mostly from NGOs (45.4%), followed by the informal sector (16.1%). Most AT users had to pay for their AP, and when asked why they did not have they AP they needed, affordability was the main reason given in all of the case studies.

# 8. In the mainstream communities, AT users are "satisfied" with the quality of the AP they have, and less satisfied with the maintenance and services

In HEPPO, it was the opposite, while AT users were "satisfied" with the maintenance and services, they were "moderately" satisfied with the helpfulness of the device and suitability for the environment.

# 9. Limited knowledge about APs and AT

During the training of data collectors and the implementation of the survey, data collectors and respondents had limited knowledge about specific assistive products and AT services. For example, in both countries, data collectors only recognised a limited number of APs at the start of the training. In Sierra Leone, this was even more prominent and most said that they had never seen most of the products in person in the country. The fact that there is a limited knowledge of AT could have affected the ability of respondents to report AT need and AT satisfaction.

It is worth highlighting that although there was limited familiarity with the AT concepts and APs, the rATA process raised awareness amongst respondents who answered the survey and saw the AP poster, which showed devices organised by impairments. In the case of the data collectors, participating in the training of the survey (including sessions on the importance of AT) and in the wider research project, raised awareness about AT. This is important as they are not disability experts, but work in low-income communities and liaise with DPOs on projects that benefit AT users and potential AT users.

# What can we learn from HEPPO, a community that has high AP coverage?

HEPPO, as a unique community organised around wheelchair users and people affected by polio, provides a rare insight into AT in a low-income community organised by and for people with disabilities in Sierra Leone. AP coverage (71.4%) in HEPPO is high in relation to other mainstream communities of the urban poor (Sierra Leone, 14.9% and Indonesia, 47.4%). We propose three hypotheses which could steer further research to explain the high AT coverage in this community, based on our experience implementing the survey and conducting interviews with community leaders.

- Severely disabled people acquired their impairments as children (average age six) and thus people have had more time to adjust to their condition and access AT.
- Most of the AP used by HEPPO residents relate to mobility, in particular wheelchairs, tricycles and crutches, which are more available in Sierra Leone than APs related to other impairments. For example, APs relating to hearing are almost non-existent. In Freetown, the main state institution working on AT provision (the National Rehabilitation Centre in Aberdeen) specialises in AP for mobility, and (along with spectacles) wheelchairs and crutches are the most widely available AP in second hand goods markets. They are also normally the focus of charitable donation by NGOs and religious organizations. However, despite being broadly more available, they were almost non-existent in the 'mainstream' communities. The rATA only found three pairs of crutches, three wheelchairs and zero tricycles among 2,076 respondents in Dworzark and Thompson Bay, and thus more research is needed to understand the low access to AT in 'mainstream' communities.
- Being organised as a community around a specific impairment could help to concentrate demand, making HEPPO residents more visible as a group, and therefore making it easier for NGOs and charitable donors to identify need. This is opposed to people with disabilities in mainstream communities, who often make themselves less publicly visible due to stigma related to disability. This could also provide a space for sharing knowledge between community members about where and how to get AP. Furthermore, it could also raise awareness in the community about the need for AP (lowering stigma, normalizing the use of AP and helping people identify the type of AP they would need by seeing others using it).

Further research into this community could help to understand how urban low-income communities could develop support mechanisms to advocate for ATs; and give insights into how to improve access to information, secure devices and address stigma around AT.

# **Appendices**

## **APPENDIX 1** rATA poster of 26 prioritised



The rATA poster contained a WHO GATE list of 26 prioritised assistive products. It was shown to respondents in a printed A3 laminated format (instead of using the app) during the survey so they could identify any products they had ("Do you currently use any assistive product?") and any products they thought they needed ("Do you think you need any assistive products you don't currently have? If yes, which product in the poster you need?"). Individuals could also name products that were not on the poster.

The original poster by WHO was not organized by impairments. DPU-UCL reorganized them by category to facilitate respondents' identification of the devices.

#### **APPENDIX 2**

Rationale for the modification of WHO rATA by DPU-UCL

The original version (rATA version 02.19) was first reviewed and tested by the wider research team in May 2019 in Banjarmasin (Indonesia) during the Pilot Workshop of the research project. We trialled a paper-based rATA in Bahasa Indonesia in three households in a low-income community, and gathered feedback from respondents, data collectors and researchers. The feedback was discussed with Wei Zhang (WHO). Final changes were made in September 2019 while training data collectors in Sierra Leone. Wesley Pryor (Nossal Institute for Global Health) supported these final changes in the app.

ITEM Original rATA		Modification	Rationale		
		GENERAL			
Consent	-	3-min video: Information and consent Consent recorded in Kobo	To deliver a clear and systematic message about the research and asking for consent.		
- Proxy - Everyone in the household	Nossal Manual suggests interviewing children under eight with proxy, but does not specify if everyone in the household answers directly or one adult answers for everyone	<ul> <li>Everyone in the household answers.</li> <li>Proxy for children under eight AND adults with disabilities who require a carer to help them communicate.</li> </ul>	- Sensitive information, so although it takes longer, each person in the household is surveyed.  - We wanted to get responses directly from respondents as much as possible. We decided only adults that have difficulties communicating would use a proxy.		
Household info	-	<ul><li>Number of people living in the household.</li><li>Information about those absent: If possible, age and gender.</li></ul>	- To have a total number of people in the area at the time of the survey. It enables understanding of the sample, especially as the time/day of the survey affects who is in the house.		
Poster	- Photos in app - Not clustered	- A3 laminated poster, clustered AP by functioning	<ul> <li>Easier to see printed than on phone.</li> <li>Cluster by function to make it easier for respondents to identify AP.</li> </ul>		

123 Survey

- Open Source and free.

Kobo Collect

- Both partner. organizations had previous experience with Kobo.

## **STRUCTURE**

Skip Logic

App

"Demand/Supply" and "Satisfaction" for any AP Specific questions per product of "Demand/Supply" and "Satisfaction" For each AP: **B.2**, **B.3**, **B.4**, **C.1**, **C.2**, **C.3**, **C.4**, **C.5** 

To collect specific data about each AP (i.e. supply demand and satisfaction)

## **SPECIFIC QUESTIONS**

Household Info

Number of people living in the household

New question:

Total universe of people (in relation to the surveys we have).

For people that report "Some difficulties" and "Cannot do at all" in any of the "Need" questions, it asks an extra question "How old were you when you first began to experience a lot of difficulties"

1.A Need

Non-existent

An invitation to the research pops up at the end of the survey when people have answered this new question (A.7)

"The researcher would like to talk to you again, can they contact you for another interview. If yes, how should they contact you?"

Household info

B.2 (now included in B.1)

Modified question: As a separate question (B.2) Was included as an option in the list of AP in B.1

B.3 (now B.2)

Modified question:

"B.3: From where did you get you assistive product?" "B.2: Where does the assistive product come from?"

Included a blank space: "Brief comment on how the person accessed the product if relevant/necessary"

To clarify the source of the AT, this is linked with the changes we did in the options as well.

We are aware that by rephrasing the question, it becomes about supply instead of demand.

We decided that a guess from the respondent is more revealing than the answer "family members", as it doesn't help us to identify the source.

The blank space was added to capture descriptive explanations.

## Modified option (in bold)

- "Gov. facility/public hospital"
- "Non-Govt. Non-Profit facility/Charity"

B.3 (now B.2)

- "Private facility/hospital/clinic"
- "Friends/Family members/Relatives"
- · "Online"
- · "Self-made"

# Changed to:

- "Gov. facility/public hospital"
- "Non-Govt. Non-Profit facility/Charity"
- "Private facility/hospital/clinic"
- "Formal sector/business"
- · "Informal sector"
- · "Home-made"

We eliminated the option "Friends/Family members/relatives" (explained above).

We changed "Online" for "Formal sector/Business" as formal businesses was not an option.

We changed "self-made" (which probably represented part of the informal sector) for "Home-made", defined as an AP made inside the home.

We included the informal sector as an option. This was defined collectively in the training workshops with the data collectors. In many countries, the informal market has a name or slang. E.g. In Sierra Leone the informal market is called Jebu. This option was important for the research as it looks at informality in the context of disability and AT access.

77

#### **APPENDIX 3**

rATA survey used by DPU-UCL (questions and instructions for data collectors in Kobo Collect)



# rapid Assistive Technology Assessment tool (rATA)

#### KEY:

Blue italic: Instructions that appear in Kobo. Highlighted: changes to original rATA

#### STEP 1:

Introduce to the person that opens the door (+18 years old). If person is under 18 years-old, ask for an adult in the house. If there are **no adults** in the house or if there is **no one** is in the house — you won't survey the household. Go to "Information about the Household" — Input "Household ID", then press "No adults in the house / No one in the house"

#### STEP 2:

#### Briefly introduce yourself and say that you're doing a survey.

"Hi, my name is \_\_\_\_\_\_ I'm working with (FEDUURP or SLURC) doing a survey about assistive technology with every person in the household. I'll show you a video which has more information about the project."

#### STEP 3

Show video (to everyone in the household if possible)

#### STEP 4:

#### Information about the household.

[Household is a person or a group that sleeps in the same building or share space inside a building, i.e. one adjoining is a household]

#### About the household (any adult):

Name:	Country:	Informal Settlement:	Household ID:	Geo Location:
Choose your name in the options	Sierra Leone	Thompson Bay Dwozarck	Enumerator Initials + 01,02,03,04 (e.g. AB01) Exception: Abdulai (AB)	Take the geolocation only 1 time for the household (skip this question for the other respondents)

1

Are there adults in the house that can be surveyed?

[If NO, finish survey]

#### Individual Consent:

- 1. Show video to anyone that hasn't seeing it
- 2. Ask for oral consent from each individual
- 3. Record in Kobo

Yes: No:

If no, finish survey for that individual [Finish survey]

## Number of people living in the household:

Everyone that lives there (not only the ones that are present)

Hint: Only ask once to the first adult. Next time, skip the question.

### About the respondent:

#### Interviewing under 18-years old:

- Between 10-17: with an adult present, get response directly from the respondent as much as possible.
- Between 0 9: proxy adult (adult answers the questions).

#### Interviewing disabled people who need their carer to help them communicate:

- Adult: Carer present get response directly from the respondent as much as possible
- Between 10-17: Carer present get response directly from the respondent as much as possible
- Between 0 –9: Proxy adult (adult answers the questions)

Please tell us how difficult you find these tasks WITHOUT any support from either a person or an assistive product

It refers to how the person finds a task without the help of someone or using eye glasses, a stick etc.

#### 1. A. Need

		No difficulty	Some difficulty	A lot of difficulty	Cannot do at all
A.1.	Do you have difficulty seeing?  (e.g. reading books, newspapers, smart phone or signs, or identifying people across the road)	The person has no difficulties seeing without eye glasses	The person has some difficulties seeing without eye glasses?	he person has a lot of difficulties seeing without eye glasses	The person can't see without eye glasses ?
A.2.	Do you have difficulty hearing?  (e.g. hearing when others talk or when answering the phone)	The person has no difficulties hearing without hearing aids or any other assistive product	The person has some difficulties hearing without hearing aids or any other assistive product 1	The person has a lot of difficulties hearing without hearing aids or any other assistive product ?	The person has can't hear withou hearing aids or any other assistive product ?
A.3.	Do you have difficulty sitting, standing, walking or climbing steps?  (e.g. sitting without support, standing up from a chair, walking independently inside or outside the house, or climbing steps)	The person has no difficulties situating, situng, situng, walking or climbing steps without the help of a person or an assistive products	The person has some difficulties sitting, standing, walking or climbing steps without the help of a person or an assistive products	The person has a lot of difficulties sitting, standing, wolking or climbing steps without the help of a person or an assistive products	The person can't sit, stand, walk or climb steps withou the help of a person or an assistive product.
A.4.	Do you have difficulty remembering or concentrating?  (e.g. forgetting appointments or medication, losing track of time, or difficulty finding places)	The person has no difficulties rememberin g or concentratin g without the help of a person or an assistive product [7]	The person has some difficulties remembering or concentratin g without the help of a person or an assistive product?	The person has a lot of difficulties remembering or concentratin g without the help of a person or an assistive product?	The person has can't remember a concentrate without the help of a person or an assistive product ?
A.5.	Do you have difficulty with your self-care? (e.g. eating, dressing, bathing or toileting)	The person has no difficulties with their self-care on their own	The person has some difficulties with their self-care on their own?	The person has a lot of difficulties with their self-care on their own?	The person has can't do any self-care activities on their own
A.6.	Do you have difficulty speaking or communicating?  (e.g. understanding others or being understood)	The person has no difficulties speaking or communicating without the help of a person or an assistive product?	The person has some difficulties speaking or communicati ng without the help of a person or an assistive product?	The person has a lot of difficulties speaking or communicating without the help of a person or an assistive product?	The person can't speak ar communicate without the help of a person or an assistive product ?

If people answer "a lot of difficulties" or "cannot do at all" it triggers the question:

A.7.	How old were you when you first began to experience a lot of difficulties?	Age: Not year	

People that answer this question are eligible for follow up. They will be asked at the end of the survey if they would like to leave their contact for the researchers.

Show POSTER

## 2. B. Demand and Supply

Do you currently use any assistive product(s)? (If "yes", tick the ones being used)

(Show the poster or GIF file - describe the images to person with visual impairment))

SN	Name of product	Image	Tick	SN	Name of product	Image	Tick
1	Alarm signalers with light/sound/ vibration			14	Manual wheelchair s - push type		
2	Audio-players with DAISYcapability			15	Orthoses		
3	Axillary/ elbow crutches			16	Pill organizers		1
4	Braille equipment		-	17	Pressure relief cushions		
5	Canes/sticks, Tripod and quadripod			18	Prostheses		
6	Chairs for shower/bath		-	19 Ramps, portable			
7	Club foot braces		-	20	Rollators and walking frames		. 1
8	Communication book/boards			21	21 Smart phones/ tablets		1
9	Grab-bars / Hand rails			22 Spectacles			
10	Hearing aids (digital) and batteries		*	23 Therapeutic footwear (diabetic, neuropathic, orthopaedic)			
11	Incontinence products, absorbent			24	Tollet chairs		

12	Magnifiers, optical/digital (including telescope)		25	Watches, talking/ touching	
13	Manual wheelchairs - basic type for active users		26	White canes	
27	Other. If yes, how many other p Max. 3 products Other 1Take a picture Other 2 Take a picture Other 3 Take a picture	products?			
	None				

If the person uses an AP, Kobo will take you to the following questions:

 $B2 \rightarrow B.3 \rightarrow B.4 \rightarrow C.1 \rightarrow C.2 \rightarrow C.3 \rightarrow C.4 \rightarrow C.5$  (If the person has selected more than 1 AP, it will go again to questions B.2 (And others) to answer for that AP)  $\rightarrow$  B. 5 (any other AP you don't currently have?)  $\rightarrow$  B. 6  $\rightarrow$  C.6  $\rightarrow$  D.1  $\rightarrow$  D. 2

If the person does not uses any AP:  $B.5 \Rightarrow B.6 \Rightarrow C.6 \Rightarrow D.1 \Rightarrow D.2$ 

2. Where does the product [e.g. wheelchair] come from? (Only 1 option)

Govt. facility/ public hospital	Non-Govt. Non- profit facility/ Charity	Private facility/ hospital/clinic	Formal sector / business	Informal sector	Home-made

Brief	comment	on how th	e person acc	essed the	product if no	ecessary/relevant:
īe wł	ho was invol	ved, enter a	nny major points	s, issues etc.	.]	
	ro trao miyor	rou, ontor o	my major pomic	, roomed blo	·a	

3. Did you have to pay for your assistive product?

Yes:	No:	
How muc	h did you pay?	(Please check that you've entered the right value

4. How far did you have to travel to get your assistive product(s)?

Less than	Between	25 - 50 Km	Between	More than
5 Km	5 – 25 Km		50 - 100 Km	100 KM
-000	The state of the s	100		

<ol><li>Do you think you need any assistive products you don't <u>currently</u> h</li></ol>	5.	Do you think	you need an	y assistive products	you don't currently ha	ve?
---	----	--------------	-------------	----------------------	------------------------	-----

Yes:	No:
If yes, v	which products in the poster/GIF you need?
Multipl	e option (all the ATs)
Other	(text for an AT that is not in the poster)

82

Would you say ...?

Very	Dissatisfied	Neither	Quite	Very
dissatisfied		satisfied nor dissatisfied	satisfied	satisfied

How satisfied are you with the quality of the service while <u>accessing</u> your assistive product? (In terms
of procedure, length of time or waiting period, quality of care and attention, and respecting your rights)

Would you say ...?

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Quite satisfied	Very satisfied
----------------------	--------------	--	--------------------	-------------------

3. How satisfied are you with the <u>repair</u>, <u>maintenance and follow-up services</u> based on your last experience?

Would you say ...?

Very	Dissatisfie	Neither	Quite	Very	Not relevant
dissatisfied	ď	satisfied nor	satisfied	satisfied	(gas raistant

4. Are your assistive product(s) suitable for your home or surroundings?

	100.0	A Contract of the		Q#Q7625454546
Not at all	Not much	Moderately	A lot	Completely

 Are you able to do what you want to do when you use your assistive product(s)? (In terms of doing household activities, self-care, going to school, college or work, visiting friends or neighbours or going for leisure and recreation)

LAST	5.38	Torran I	(25.0	
Not at	Not	Moderately	A lot	Completely
all	much			

6. Overall, how would you rate your health and well-being:

Very Bad	Bad	Neither good	Good	Very good
very bau	bau	nor bad	Good	very good

## 4. D: Recommendations (optional)

D.1. Do you have any comments regarding any aspects on improving access to assistive product(s) in your country

(Please write up to three action points.)	
1.	
2	
4	

	i <mark>nything that would stopped you from using AT other than price and availabilit</mark> vrite <u>up to three</u> action points.)
1	
2	· · · · · · · · · · · · · · · · · · ·
3	

# The survey is now completed. We thank you for your participation

For respondents that answer "a lot of difficulties" or "cannot do at all"
[This person is eligible for follow up. Please ask the following questions]:
The researcher would like to talk to you again, can they contact you for another interview. If yes, how should they contact