


The informal economy as a provider of assistive technology: lessons from Indonesia and Sierra Leone

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Summary

Promoting the use of assistive technology (AT) is crucial for the health and well-being of users, but there is a huge global problem of unmet need for AT. In this context informal (unregulated) providers of AT play a significant role of meeting AT user need, particularly in less-resourced settings. This study draws on research into formal and informal AT provision in low-income urban communities in Indonesia and Sierra Leone to explore the potential of informal providers in addressing unmet need. Specifically, it looks at the different performance of formal and informal providers regarding the availability and the adequacy of AT that they provide. The study concludes by proposing further research into the scope for coproduction of AT between formal and informal providers.

Lay Summary

Assistive technology (AT) (e.g. wheelchairs, hearing aids, or products for people with visual impairments) are crucial for the wellbeing of users, but there is huge and growing unmet need for AT globally. In low-income settings many users access AT from the informal (unregulated) economy, which tends to provide AT in under-served communities, and at lower cost, helping to address this gap. However, AT from informal providers often fails to meet minimum product standards and/or lacks associated services such as assessment, fitting, user training, maintenance and repairs. On the other hand, many users of AT from informal sources value, in addition to low cost, some other features, such as their ability to customize assistive products and innovate in product development. This study therefore proposes exploring ways in which formal and informal providers of AT could work together to improve access at the same time as ensuring the safety and quality of AT for low-income users.

Key words: assistive technology, informal sector, global South, Indonesia, Sierra Leone

UNMET NEED FOR ASSISTIVE TECHNOLOGY

Assistive technology (AT) refers to the systems and services for the delivery of assistive products (AP) which are

‘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' (WHO, 2016, p. 1).

Common examples of AP include hearing aids, wheelchairs, pill organizers, prosthetic and orthotic devices, or spectacles, and there has also been an increasing focus on the use of information and communication technologies as AP (Darcy *et al.*, 2016). The World Health Organization (WHO) coordinated GATE (Global Cooperation on Assistive Technology) initiative has identified 50 priority AP as crucial for people's functioning, which they propose should be made available at affordable price (WHO, 2016).

The GATE initiative's focus on the need for AT to be widely accessible, and affordable, responds to their importance for enabling the activities of people with difficulties in functioning (e.g. many older people and people with disabilities or chronic conditions). A significant body of research has demonstrated the importance of AT for promoting the health and well-being of all people who need/use AT, with important implications for users' independence, and also for users' ability to communicate and be connected, for participation in social activities, work and education (Louise-Bender Pape *et al.*, 2002; Lenker *et al.*, 2013). In addition to their importance for users, research has also suggested the importance of AT for the health and well-being of care-givers (Mortenson *et al.*, 2012). Building on this, it has been argued that access to AT should be understood as a human right (Borg *et al.*, 2011).

However, despite consensus on the importance of AT, there is a significant global gap in access to AT for those who need it. According to WHO, more than a billion people currently need one or more AP, but only one in ten of them actually have access to the AP that they need. Looking forward, it is estimated (due to an aging global population and growing incidence of noncommunicable diseases) that this level of need will increase rapidly, with more than two billion people needing at least one AP by 2030 (WHO, 2021).

In parallel to, and reinforcing, the problem of unmet need is a frequent reality of inadequately met need. In many cases, even where people do have access to AT, it is either not suitable for their specific requirements, or even of sufficient quality to function well for any user. The result is that inadequate AT is not used, as has been highlighted by a significant focus on abandonment in the AT literature (Scherer, 2002; Petrie *et al.*, 2018; Sugawara *et al.*, 2018), or *is* used due to lack of alternatives, but with negative and at times disastrous consequences, such as morbidity and premature mortality resulting from pressures sores due to use of inappropriate wheelchairs (Øderud, 2014).

Unmet need for, and inadequate provision of, AT therefore represents a huge global challenge, and these problems are even more acute in less resourced settings (Eide and Øderud, 2009; Visagie *et al.*, 2017). In this context global initiatives are having to engage with how to rapidly promote access to AT to those with unmet need, at the same time as ensuring that the AT that *is* made available is adequate—i.e. that it meets minimum product standards and is properly prescribed, and provided, to ensure that it works for users.

Strategies to address need for AT necessitate working with the very diverse group of actors currently involved in AT provision, cutting across government agencies (notably those concerned with health and with social policy), private enterprises, and civil society entities including non-governmental Organizations (NGOs), user groups, religious bodies, and philanthropists. Policy approaches to extending access, at the same time as ensuring the quality of AT, first require an understanding of the range of AT providers which exist, and their existing capacities.

To support countries to respond to the 2018 World Health Resolution on AT, 'to develop, implement and strengthen policies and programmes, as appropriate, to improve access to AT within universal health and/or social services coverage' (World Health Organization, 2018), WHO has developed an AT capacity assessment tool (ATA-C). The ATA-C is a system-level tool to assess the status in a country in relation to AT policy, financing, procurement and service provision. The tool has been implemented in 18 countries since 2019 and findings have driven subsequent policy and program-related actions (Bostian, 2020).

While these country capacity assessments and other global initiative have been primarily focused on public sector health and social institutions, formal private enterprises, and registered NGOs, this study argues that another sector that is significant in provision of AT, and particularly so in less resourced settings, is the *informal economy*. However, to date there has not been a significant strategic focus on addressing the informal economy as a de facto provider of AT in many contexts. On this basis, the next section defines what the informal sector constitutes, how it has been characterized in academic and policy literature, and discusses some patterns in its role in AT provision and their implications for interventions to extend access to AT.

AT AND INFORMAL ENTERPRISES

The informal economy has been a focus of both academic research, and policy initiatives, in relation to a range of

concerns, including: the predominance of the informal economy as an important means of economic production and source of livelihoods in many countries (Benjamin *et al.*, 2014; ILO, 2018); the need to extend secure livelihoods and decent work to those working in the informal economy (Chen, 2012), occupational health and safety measures for informal workers (Lund *et al.*, 2016), or the relationship between the informal economy, urban planning and spatial justice (Roy, 2005).

However, debate persists as to the definition of the informal economy. According to the ILO (2013), the two main schools of thought define the informal economy in terms of, on the one hand, the lack of state regulation and on the other, the (informal) organization of production and accounting practices. However, of the two, the focus on the lack of state regulation is the most widely held understanding. ‘The prevailing definition accepted across disciplinary and ideological boundaries is that the informal economy refers to income generating activities that operate outside the regulatory framework of the state’ (Meagher, 2013, p. 2).

If the informal economy is defined as that part of the economy that is significantly less subject to state regulation, what are the implications of the informal economy for AT provision in low resource settings? This study looks at two key dimensions of AT, namely the *availability* and the *adequacy of AT*, and considers the implications of informal provision for each of these.

Availability of AT can refer to the extent to which those who need AT are able to access it, in a timely manner, without them or their households having to make unreasonable sacrifices to do so. A key issue is whether AT is treated as a commodity, or is *decommodified* i.e. seen as a social right and so accessible regardless of the person’s economic means to purchase (Esping-Andersen, 1990). Where AT remains treated primarily as a commodity, rather than a decommodified (human) right, it is likely that a key factor for availability is *cost*. Given that goods and services produced in the informal economy are likely to be cheaper than those produced in the formal economy (Williams and Martinez-Perez, 2014), as informal producers do not incur the costs of state regulation such as taxation, or minimum wages, one key factor that is likely to make informally produced AP more available is lower cost. However the capacity of the informal sector to produce technically complex AP and related service delivery may mean that some AP are simply not available via informal markets—i.e. this availability is limited to the types of AP that informal markets have the capacity to deliver.

Adequacy of AT, on the other hand, can refer to the extent to which AT meets the needs of users—i.e. AP

that optimize a person’s functioning and/or preventing secondary health issues, and in turn, enable them to achieve the aspirations that they value. Given the importance of customization of AP to meet specific needs (Scherer, 2002), the ability to adapt AP for each individual could also be considered a component of adequacy. Another important factor related to adequacy is ensuring that AT (both AP and related services), meets minimum standards to ensure that it is safe and of adequate quality (de Witte *et al.*, 2018 de). As many minimum standards, such as qualifications of AT personnel, or product standards, are applied through some form of regulation, it would seem logical that AT provided through informal markets is less likely to be compliant as it is less subject to regulation. Furthermore, it could also be expected that informal enterprises lack the institutional capacity and skills to produce, deliver or customize more technically complex AP (such as hearing aids, or mobile phone-based technologies).

Looking at how the two criteria of availability and adequacy might in theory be affected by informal AT provision, therefore, it appears that there is a tension between informal providers being likely to provide AT at a lower price, and therefore making it more available to users, at the same time as offering AP and related services that are less adequate in terms of their quality and suitability to users’ needs.

To explore the extent to which this holds in practice, the next section of this study will use research conducted in Indonesia and Sierra Leone on informal markets for AT to discuss some of the patterns that emerged in relation to AT coverage amongst low-income urban citizens, as well as how informal providers of AT perform in terms of *availability* and *adequacy* of AT provision vis a vis other providers.

AT2030 INFORMAL MARKETS STUDY

This study draws on the AT2030 Research Programme (Grant number 1720325), which aims to support access to life-changing AT at scale, and was funded by the UK Department for International Development (DFID) and delivered by the Global Disability Innovation Hub (GDI Hub). The specific AT2030 research project which is the focus of this study was a study into *Informal Markets for AT*, which supplemented a series of AT Country Capacity Assessments undertaken as a collaboration between the GDI Hub and the WHO using WHO’s Assistive Technology Assessment—Capacity (ATA-C) tool (<https://www.who.int/tools/ata-toolkit>).

The supplementary informal markets research was conducted in Indonesia and Sierra Leone by a team from

the Development Planning Unit (DPU) of University College London (UCL) and the NGOs Kota Kita (in Indonesia) and the Centre of Dialogue on Human Settlement and Poverty Alleviation (CODHSAPA), in Sierra Leone. It aimed to understand how low-income urban citizens in the two countries access and use AT, and the role that informal markets play in this. The focus on urban settlements responds to the fact that the majority of the world's population now lives in urban areas (55% in 2018) and that towards 2050 urbanization is forecast to be most rapid in low and lower middle income countries (UN DESA, 2019) suggesting that this is where we can expect to find growing low-income populations with unmet need for AT in the future. A full account of the research is available in two country reports (Walker *et al.*, 2020a, 2020b).

The research was conducted in six cities: Jakarta, Surakarta, Yogyakarta, and Banjarmasin in Indonesia and Freetown and Bo in Sierra Leone. Focus group discussion and interviews were conducted with AT users from the two countries (a total of 38 women and 55 men with a range of disabilities and associated AT needs). AT user participants were reached through referrals by organizations of persons with disabilities (OPDs) contacted during the research, as well as the existing networks of the local research partners, both of which have established working relationships with OPDs. AT users identified during the quantitative survey in four low-income settlements (see below) were also invited to join FGDs. A total of 48 semi-structured interviews based on an adapted version of the ATA-C questionnaire were also conducted with actors, from government (5 in Indonesia and 4 in Sierra Leone), OPDs (6 in Indonesia and 5 in Sierra Leone), non-governmental organization (NGOs) (3 in Indonesia and 4 in Sierra Leone) and formal entities (5 in Indonesia and 5 in Sierra Leone) and informal entities (7 in Indonesia and 4 in Sierra Leone) all involved in different ways with the provision of AT and AT policy, programming and advocacy. Interviewees were identified through referrals by AT user participants in FGDs; the existing networks of the local partners the Federation of the Urban and Rural Poor (in Freetown) and Kaki Kota (in Banjarmasin); and through a snow-balling strategy.

In addition, as part of the AT2030 research, a sample survey was undertaken in four low-income urban settlements, two in the city of Banjarmasin and two in Freetown. The settlements were selected by local partners as typical low-income urban settlements, without having special disability-related features (such as high disability prevalence, or the presence of disability-related services and facilities) and as such were intended to

give an insight into AT access and use in 'ordinary' urban settlements. The survey was undertaken using the WHO Rapid Assistive Technology Assessment (rATA) tool (WHO, 2021) which assesses both AT need in relation to six functional domains (vision, mobility, hearing, remembering/concentrating, self-care, and speaking/communicating) and existing patterns of AT access. Data for the rATA survey was collected using KoBo Toolbox, with data collection on smartphones. A number of adaptations were made to the original rATA tool, including the addition of informal providers as an option for the rATA question on AP sources. The rATA tool was modified and trialled by Ignacia Ossul (Development Planning Unit, University College London) and adapted for the Kobo app by Giulia Barbareschi and Cathy Holloway (Department of Computer Science, University College London), and codes were adapted and updated in the field by Wesley Pryor (Nossal Institute for Global Health) Mark Carew (Leonard Cheshire) cleaned the data and performed statistical analysis.

The rATA survey was undertaken in Indonesia by a team from the national NGO Kota Kita, with a team of enumerators from their city-level partner organization Kaki Kota and in Sierra Leone by a team from the Federation for the Urban and Rural Poor (FEDURP) with support from the Sierra Leone Urban Research Centre. In Indonesia, 2046 individuals answered the survey (94% of those approached), with just over 5% of declining the survey ($N=117$) and consent was not sought where no adults were present ($N=4$). In Sierra Leone data were collected from 84% of respondents ($N=2076$) who were asked to participate in the survey. Just over 3% of individuals declined to provide consent ($N=79$) and consent was not sought where no adults were present ($N=306$; 12%).

Ethical approval for the research was given by the UCL Research Ethics Committee (approval number 5367/001). To address complex issues relating to consent in research with people with disabilities, we drew on Cameron & Murphy's principles (2007). Transcripts were anonymized and photographic and video material were only used with the consent of participants.

The study generated a range of findings about informal markets for AT, including some findings specific to this paper's focus on AT coverage and on the adequacy of AT provided by formal and informal institutions. While the case material presented here cannot be generalized across low-income urban settings in the global South, it contributes to the scant existing body of knowledge on AT in low-income urban settings, and, drawing on Flyvbjerg's (Flyvbjerg, 2006, p. 227) assertion that 'A

purely descriptive, phenomenological case study without any attempt to generalize can certainly be of value... and has often helped cut a path toward scientific innovation', we present the findings of this context-specific study to provoke future lines of enquiry for AT policy development. Our findings and their implications for AT availability and adequacy are covered in the following sections.

Coverage of at from formal and informal sources in Indonesia and Sierra Leone

In terms of the scale of AT use, neither country has national level data on AT provision. In the absence of national level quantitative data on AT use, the study drew on the rATA survey, as well as focus groups and interviews with OPDs and AT users, to get an understanding of levels of coverage and sources of AP for low-income urban citizens in the two countries. In both countries, there was a high level of unmet need for AT. Unmet need was defined as the percentage of respondents from the rATA survey who answered 'A lot of difficulty' or 'Cannot do at all' in relation to any of the six functioning domains (vision, hearing, mobility, cognition, self-care, or communication) and indicated that they needed, but did not have, any one of the APs in the rATA questionnaire poster. Unmet need was particularly high in Sierra Leone where almost a third of the individuals in the rATA survey who reported some difficulty (28.7%; $N=97$), four-fifths of individuals reporting a lot of difficulty (80.5% $N=66$) and all of the participants who reported cannot do at all (100%; $N=9$) in any one of the domains covered by the rATA had unmet need for AP. In Indonesia, unmet need was less extreme, but still significant, with less than three quarters of individuals who experience a lot of difficulty in any one domain and less than two-thirds who cannot function at all in any one domain having access to a single assistive product. Notably, in both countries unmet need increased for those with higher reported functional limitations. The high level of unmet need in both countries reflects the lack of availability of affordable commercial providers of AT, and the limited reach of subsidized or free AT from state providers or NGOs and civil society.

In terms of state provision, while neither of the two countries have laws to ensure citizens' access to AT as a right, both countries do have social policies and health policies designed to support access to AT, including access of those on low incomes. However, in Sierra Leone these are extremely limited in scope and mainly refer to provision of AT in emergency hospitals or very limited provision through the country's three National

Rehabilitation Centres, which have limited human resources and equipment, and also charge fees to AT users for cost recovery. The 2011 Sierra Leone Persons with Disability Act guarantees disabled people 'free medical services in public health institutions', which could imply access to free AT services, but disabled interviewees who participated in the study informed us that such free health services are not offered in practice. Official Development Assistance (ODA) projects are an important source of AT, primarily through provision of AP to students as part of a number of internationally funded education programmes. However such interventions are project based and so do not represent a permanent feature of the AT systems in the country.

Formal private sector provision in Sierra Leone is limited in scope, through fee-charging private hospitals, a few registered opticians and only one licensed medical supply shop in the country (Index Medical and Laboratory Equipment) which offers new wheelchairs, walkers, and crutches as well as paid, on-demand training in AT use from a retired physiotherapist from one of the public hospitals. In practice in Sierra Leone the main source of free (unpaid) access to AT for low-income people is charitable donations from NGOs, OPDs, religious bodies, and private individuals.

In Indonesia, formal access to AT is more substantial, though, as the rATA survey suggests, still fails to meet the needs of many low-income users. The Ministry of Social Welfare and its local Social Departments have annual budgets for AP, which are normally used for public donations of AP such as wheelchairs and crutches during public occasions in event such as International Disability Day—however such provision is ad hoc and with limited coverage. In addition there are a number of 'balai' (rehabilitation workshops) which both produce AP and fit and train users, such as the national prosthetic and orthotic (P&O) Balai in the city of Surakarta in Java. There is also a range of national health insurance schemes, including the BJPS, which offer subsidies for AP, and those on low incomes who qualify for a 'Red KIS card' are eligible for free AP schemes from the Ministry of Social Welfare and its local Social Departments. Accessing the KIS red card, however, is a highly bureaucratic process which involves up to 12 steps of registration, and furthermore some groups, such as internal migrants, or those living in remote rural areas, may face administrative barriers to registration, which limits the reach of this scheme. There are some attempts to streamline this in specific municipalities, notably in Yogyakarta with its 'Jamkesta' scheme designed to increase access to low-income AT users, which is a

promising avenue to extend access to AT for low-income users.

According to Indonesian Ministry of Social Welfare staff interviewed during the study, the planned national budget for AT in 2020 was IDR 36 billion (USD 2.3 million), including both funds for the direct provision of AT and funds for AT users to buy AP and be reimbursed through the Bantuan Sosial Alat Bantu scheme and the BJPS insurance scheme, which can clearly have only a small impact in country with a population of 270 million and 21.8 million disabled people.

In parallel, in Indonesia, there is a quite well developed formal private sector provision of AT in the country, including, for example, a range of opticians and hearing aid providers, but these are unaffordable for low-income users and while easily accessible in Java, do not have a strong coverage over all regions of the country. Furthermore, the Indonesia rATA survey results showed that most users pay for their AT from all sources, (including government facilities and public hospitals), with the exception of NGOs, where only about a third of respondents paid. This heavy reliance on self-finance for AT is linked to the high level of unmet need. Of the 117 individuals with an unmet need for AT in the rATA survey, more than half of respondents ($N = 63$; 53.8%) cited affordability as an explanation.

For those respondents who *did* have access to an AP in the two countries, the informal sector was the main source in both countries. 65.3% of respondents in Indonesia, and 30.8% in Sierra Leone, had acquired their AP from informal sector providers. This was significantly higher than the other main sources, such as formal businesses (24.4% in Indonesia and 16.9 in Sierra Leone) government facilities/public hospitals (3.2% in Indonesia and 27.7% in Sierra Leone) or private hospitals (5.2% Indonesia and 15.4% in Sierra Leone). In the survey, these figures were based on locally understood definitions of the informal sector, which in both countries referred to small unregistered businesses and street and market traders. Some of the main informal AT providers cited in Sierra Leone were the large imported second-hand goods traders as well as tradespeople such as carpenters and motor mechanics who produce and repair basic AP. In Indonesia informal AT markets were more likely to include new, but unregulated, AP for sale in small shops and traditional markets (e.g. spectacles and crutches, or hearing amplifiers), as well as the provisions of related services (e.g. eye tests) by providers without formal qualifications.

However, if we take the more academic definition of informal providers as AT providers that are *not regulated* by relevant medical bodies then this would also

include many NGOs, OPDs, and religious organizations involved in AT provision. Additionally, in Sierra Leone there were a number of respondents with self-made AP which clearly also falls within the informal sector as an unregulated source of AP. This would increase the total informal provision of AT picked up in the rATA survey to 67.2% in Indonesia and 40.1% in Sierra Leone.

To understand why there was a higher use of informal than formal AT providers amongst the low-income urban participants in the study in both countries, we asked participants to identify and rank the characteristics of AT providers that determines their choice of AT providers during Focus Group Discussion sessions. Some of the most commonly identified factors which explain the higher use informal providers can be related to the two dimensions of AT provision that are the focus of this paper: *availability*, including cost, but also others highlighted by participants such as physical accessibility, and speed; and *adequacy*, including factors highlighted by participants such as quality, variety, and customization. These are explored in more detail in the following sections.

Availability of at from formal and informal sources in Sierra Leone and Indonesia

As discussed above, while there are public and civil society schemes giving free access to AT in both countries these are limited and most users have to pay for their AT, even when these are from public sources. For example in the rATA survey, for those respondents who had acquired their AT in a 'Government Facility/Public Hospital', 72.2% in Sierra Leone and 90% in Indonesia had had to pay. Given the association of disability with poverty in many contexts (Groce and Kett, 2013), cost is likely to be a key factor in determining choice of AT provider. This was the case in the communities in which the study was undertaken, where participants confirmed that AT *cost* is a key criteria for the availability of AT for low-income users. In both countries, informal providers consistently offered AT and AT services (including both new and second hand AP) at lower prices than formal private businesses, whose high costs are beyond the reach of low-income users for many AT.

The main source of low-cost informal AP and related services in Sierra Leone are businesses in the large imported second-hand goods markets, which sell a range of AP (such as wheelchairs and crutches), although users need to hunt these out as there are not specialist second hand AR traders in the markets. In addition a number of informal trades make, modify and/or repair AP (e.g. carpenters and car mechanics) at low cost, and sometimes for free if they know the AT user. In Indonesia informal

AT are also provided by tradespeople such as carpenters and car mechanics, as well as small shops in traditional markets selling new, (locally produced and imported) low cost AP, and these tend to be significantly cheaper than other sources.

For example, in Indonesia as formally provided hearing aids are highly unaffordable for low-income users, and only partly covered by health insurance schemes, many users instead buy medically unapproved in ear amplifiers from informal shops and markets. However, while ATs secured from informal markets are lower cost in both countries, some AP and services are simply not available in such markets (e.g. prosthetics in both countries, or hearing aids in Sierra Leone) and there may be trade-offs with quality as will be discussed in the following section.

Another criteria which was valued by AT users was *physical accessibility*, which was particularly important for many of the AT users involved in the study who found travel within their cities and to different parts of their countries expensive and difficult. Many informal AT providers (itinerant opticians, tradesmen such as mechanics and carpenters) are based in, or visit the communities where low-income AT users live. In contrast, most specialist public providers are limited to major cities. For example in Indonesia there are only six wheelchair providers conforming with WHO standards in the country, which are all in Java, whereas there are informal providers selling lower quality wheelchairs across the country often without associated provision services. Even where the AT user lives in the same city as the AT provider they may not be able to reach it—for example one of our respondents (a wheelchair user in Freetown) told us that she cannot access the National Rehabilitation Centre by public transport, as minibus and keke (motorbike tricycle) drivers refuse to take her wheelchair on board, and so she is only able to travel there by pushing her wheelchair which takes a couple of hours each way.

A final criteria raised by many participants in Indonesia in particular, where subsidized or free AT from public sector sources are more available than in Sierra Leone, was the *time* that has to be invested in securing these due to the complex bureaucracy to determine eligibility for government schemes, and delays in receiving them due to the annual rhythms of government budgets. In contrast, buying AP means that such delays can be avoided, but for those on low incomes this is only possible from informal providers.

Adequacy of at from formal and informal sources in Sierra Leone and Indonesia

In terms of the adequacy of AT, participants in the study highlighted a number of criteria that were important to

them in their choice of AT providers, including *quality* of products and services, and the *variety* and *customization* of AP.

In terms of quality, some serious concerns with the quality of specific AP from informal providers were highlighted by participants (e.g. the very poor quality of hearing amplifiers in Indonesia, or of many second hand AP such as wheelchairs purchased in markets in Freetown). The research also highlighted a number of more general issues related to the quality of AP and AT services in the informal economy: informal AT services are not formally assessed for their product standards or staff qualifications; there is no consumer protection or recourse in case a product is faulty or harmful, and; informal providers generally provide AP without any assessment, user training, or other related support as part of their service to AT users.

However, informal AT providers were not always linked with poor quality by users. For example in Indonesia, many AT users preferred the crutches that they bought in informal market to those provided by local (municipal) Social Departments which they regarded as being of poorer quality (with brittle metal and rubber tips that wear down quickly). On the other hand, the idea that formality, through regulation of providers, necessarily leads to better quality was questioned by formal AT providers in Sierra Leone. In this case, formal commercial businesses such as pharmacies must register with and get approval from the government to sell their products, and imported products must be signed off at the port of entry by the Sierra Leone Standards Bureau (SLSB) who issue a certificate of standards. However, there are no norms for minimum AP product standards and the SLSB staff only have the capacity to test medical products. The formal AT providers saw this regulation more as a source of income for the state than a means of regulating the quality of AP that are imported into the country.

Other criteria that participants highlighted as important in the adequacy of AT were the *variety* and *customization* offered, and these were in fact positively associated with informal AT providers. Scherer highlights that 'it is essential to define the consumer's perspectives of the most desired outcomes' (2002, p. 3) and our study suggests that informal providers are often more responsive to AT users' perspectives than formal providers.

Some formal AT providers do customize AT to specific users [e.g. hospital prescribed AT, AT from the Balai in Indonesia and the NRC in Sierra Leone providing prosthetics and orthotics (P&O), or some specialist wheelchair NGOs in Indonesia such as United Cerebral

Palsy (UCP) and Ohana, which customized and fit to user needs]. However, in many cases public and philanthropic provision is led by the mass donations of AP (i.e. led by the product rather than the user) which means that users are found for products, rather than products being selected for and customized to users. This is usually linked to poor customization, lack of user training, or access to maintenance and repair services, and so result in many cases of abandonment. In contrast, in both countries many AT users commission informal tradespeople to adapt and customize AP such as crutches, or wheelchairs in order that they are more suitable to their needs.

In terms of variety, offering AP with functions and features that are most suitable to users' needs, a number of informal providers scored strongly. In Indonesia in particular informal businesses are positively associated with developing many AP that are more suitable for users because they are associated with AT innovation by disabled entrepreneurs who understand the needs of users and innovate accordingly. Such businesses may lack staff with formal qualifications or business structures, but they make an important contribution to AP innovation due to their willingness to customize AP for users' needs. Notable examples of disabled innovator led enterprises in Indonesia include Kaiden, who makes products for the blind, and Difabike, which makes motorbike tricycles.

Kaiden is an entrepreneur who manufactures good quality and relevant products for the blind from his workshop in his home in North Jakarta. He began developing AP for blind people when he suffered an eye injury at work in 1987. Today he manufactures and provides a range of products including white canes, talking watches and clocks, chess sets for the blind, and maps and globes for the blind. As he is blind himself and a member of the blind people's OPD, Pertuni, he has a good understanding of the needs of blind AT users. For example, in the context of massage being a very common form of employment for blind people in Indonesia, he has developed massage equipment specially designed for blind users (e.g. talking thermometers and blood pressure gauges). The quality and relevance of his products is reflected in the fact that he exports them, on order, to Japan, Canada, and Singapore, and intermediary institutions and charities, including formal AT providers, buy his AP to distribute across Indonesia through formal, including state, programmes. However, his business continues to operate informally without legal registrations, and with no official brand or trademark.

Difabike was established in 2014 in Yogyakarta as a motorbike taxi service that employed disabled drivers to serve disabled customers and to support the production

of motorbike tricycles adapted to the specific needs of disabled users. In the informal markets study, mobility impaired respondents ranked motorbike tricycles as extremely important for their ability to work, go out in public and move around their cities, and be visible and socially active. However, motorbike tricycles are not formally recognized as an AT in Indonesia, and so are not offered by any formal AT providers. Difabike has designed various models, customized for a range of users, with help from two local universities (UGM and UST). In 2015, with the support of the UGM University Research Centre on Transport Studies, Difabike signed a memorandum with the Department of Transport (DoT). This memorandum allows them to operate, but it has not secured the official recognition they need to scale up their operations so Difabike remains limited to providing services to disabled passengers, and the DoT will not register Difabike tricycles as legal vehicles, as they are customized to fit the needs of specific disabled users and do not meet a uniform standard. Finally, as a small OPD, the process to register as a private limited company is complex. Therefore, while Difabike, like Kaiden, offers AP which are highly valued by disabled users, it remains an informal enterprise and its scope to scale up is limited.

Conclusions: Working with the informal sector—displacement or co production?

The study suggested that there is extremely limited coverage amongst low-income citizens in need of AT in Sierra Leone, and relatively limited coverage in Indonesia, due to resource constraints and lack of institutional capacity. In this context, informal providers play a key role in basic AT provision in both countries.

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

As the discussion above suggests, the performance of informal providers of AT in Indonesia and Sierra Leone

vis a vis formal providers is mixed, in terms of the *availability* and *adequacy* of the AT that they offer. The AT offered by informal providers tend to be cheaper and more physically accessible, but they may be of lower quality and more technically complex AT may be unavailable from these providers. At the same time, informal providers can offer more services around customization of AP and, in particular in Indonesia, are associated with innovation leading to a greater variety of AT on offer, including products that are specially suited to AT users' needs and aspirations.

Given the mixed outcomes of AT provision by informal actors, what are the implications for global and national initiatives working at a policy level to promote wider access to and use of AT? As informal providers are clearly playing a strong de facto role in AT provision (and were the main source of AT for low-income AT users in both countries) this could imply thinking about how to draw on informal providers as a resource, while remaining cognizant of their limitations. This kind of pragmatism is already employed by many AT providers on the ground—for example, a study in South Africa found that in the context of lack of availability of AP, AT professionals will use alternatives that are locally available (Van Niekerk *et al.*, 2019).

The findings have highlighted the diversity of AT providers in the two countries, including many operating outside the 'formal sector' which are left out of government-led actions towards improving access. As a first step to address this gap, the findings have informed a new iteration of the ATA-C tool to better capture informal provision of AT (see: <https://mednet-communities.net/gate/ata-c>). However, documenting and supporting informal providers of AT remains an area that merits further investigation. For example, exploration of the potential of WHO's *Training in Assistive Products (TAP)* [[https://www.who.int/news-room/feature-stories/detail/personnel-training-in-priority-assistive-products-\(tap\)](https://www.who.int/news-room/feature-stories/detail/personnel-training-in-priority-assistive-products-(tap))] online learning resource as a tool to build the awareness of informal providers on minimum service standards. While there is literature more generally on the importance of the informal economy in providing crucial resources and services to the poor, such as housing (Berner, 2001), or employment (ILO, 2018), in the past the dominant policy response to the informal economy has been to police it and displace it (Obeng-Odoom, 2011). In more recent years a growing recognition of the importance and persistence of the informal economy has led to calls to work with the informal economy in processes of co-production in an effort to realize 'positive hybridity' (Song, 2016) in the relationship between formal and informal actors.

The findings of our research into informal AT providers in Indonesia and Sierra Leone confirm that, while there are risks associated with quality of their AT, there is a promise in the contribution that can be made by informal providers. Future research into informal AT provision could explore in more detail how access to AT varies by type of disability, gender, age, location and how such barriers might be overcome based on local contexts. Further exploration is also needed on how the role of AT provision by informal actors can best be co-produced or co-governed by formal actors working in the AT sector, such as Ministries of Health and Social Welfare, or disability NGOs. There is a delicate balance to be struck between strengthening regulation of AP and services without inadvertently adding barriers or disrupting existing provision that is meeting people's needs. A key question here, which merits further investigation, would be *how can the benefits of informal AT providers in providing broader and less expensive access to otherwise unserved populations be promoted whilst protecting AT users from unsafe products and services?*

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