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# Repair strategies for assistive technology in low resource settings

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#### **ABSTRACT**

Purpose: To investigate the practices of repair that exist for users of mobility assistive products in low resource settings, as well as the psychosocial impact that the repair, or non-repair, of these devices has on users' lives.

Materials and Methods: This article collates data on repair practices and the responses from participants on the topic of repair from studies conducted by the authors across four different low resource settings in Kenya, Uganda, Sierra Leone, and Indonesia. This data was then analyzed to identify the common themes found across geographies.

Results: Three major models of repair practice emerged from the data: "Individual or Informal Repair in the Community"; "Local Initiatives"; and "Specialist AT Workshop Repair". Additionally, the wider impact on the participants' lives of "Problems & Concerns with Repair"; "Experiences of Breakages & Frequencies of Repair" and the "Impact of Broken Devices" are explored.

Conclusions: The results of this analysis demonstrate the paramount importance of community-based repair of devices, and how despite this importance, repair is often overlooked in the planning and design of assistive products and services. There is a need to further incorporate and support these informal contributions as part of the formal provision systems of assistive device.

#### > IMPLICATIONS FOR REHABILITATION

- A lack of available specialist repair services in low resource settings hinders the potential impact of assistive technology provision systems.
- Community-based repair is the major route by which assistive devices are repaired in low resource settings.
- Appropriate community-based repair strategies should be incorporated into and supported by the formal assistive technology provision models in order to optimise outcomes.
- A lack of data on outcomes across the lifecycle of assistive products hinders progress on improving focus on follow-up services - in particular repair & maintenance.
- By supporting community-based repair, repairs that are inappropriate for that approach could be better directed to specialist repair services.

#### **ARTICLE HISTORY**

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repair; community; assistive technology; wheelchairs; prosthetics; informal settlements

# Introduction

Over one billion people need one or more assistive products to fully participate in society, with a projected two billion in need by 2050 – yet only 5–15% of people have appropriate and affordable access [1]. Assistive products enable people with difficulties in functioning to live healthy, productive, independent, and dignified lives [2]. They facilitate participation in education, the labour market and social life, and can reduce the need for formal health and support services, long-term care and burden on carers [3-5]. Assistive products and the services to provide these are collectively termed assistive technology (AT) by the WHO [6]. The service element of provision refers to various processes - fitting, device training and of particular interest to this paper - repair & maintenance. Without appropriate and affordable AT, people with disabilities, older people and others in need of assistive products are often excluded, isolated and locked into poverty; and the burden to society of the resulting morbidity and disability increases [7].

The impact is considerable and wide-reaching – for example Tebbutt et al. warns that without promoting the availability of assistive products the Sustainable Development Goals cannot be achieved equitably or at all [8]. There are myriad challenges for AT provision: it is usually a long-term (sometimes lifelong)

requirement; AT can be rejected by the user at any point in time if the benefits it offers are outweighed by the disadvantages (in the extreme case, the AT breaks and hence offers no benefit); the provider typically has little or no knowledge about whether or not the AT meets a user's needed; and AT support may require expertise beyond the traditional bounds of healthcare professions [9]. There is little known about these factors impact on continuity of AT access or are a factor in delivering on the SDGs. In this paper we focus on one key factor, namely repair services.

This paper focuses on the local repair of assistive products in low resource environments. We review the existing literature on the repair of assistive products in low resource settings, and briefly discuss the "Right to Repair" movement. This movement is being enacted globally, in the form of governmental policies and informal movements aimed at making reparability a lawful right for consumers, and an obligation for manufacturers, and the likely impact on the design for repair of assistive products in the future [10,11]. We report our study, which constitutes primary research carried out in four low resource settings (Kenya, Uganda, Sierra Leone, and Indonesia) as part of a global research programme into AT access which included collecting data on communitybased repair of assistive products. Finally we discuss our results and consider the implications on the design and delivery of assistive products in low resource settings.

# **Background**

While any AT service provider & user surveys highlight the gaps in service for assistive products regarding repair & maintenance – there are few studies of repair or repair-centred interventions for assistive products in low resource settings. Toro et al. describe an interesting pilot study on implementing their "4R model" Repairing, Reusing, Recycling and Retrofitting wheelchairs at a service point in Mexico, with a view to understanding if this could be profitable [12]. The team also investigated the frequency, causes and consequences of wheelchair breakdowns in a paediatric clinic in Mexico. They found that product reliability and strength was a problem and wheelchairs often were not appropriate for the environment, however various failures could have been prevented with appropriate maintenance [13].

In Indonesia, Toro found in a N = 142 cohort study that at a 6month follow up after receiving a new wheelchair 34% of participants self-reported needing more than one repair. The majority (70%) reported not completing the repairs; and most of the repairs that were completed were done by the user/caregiver [14]. The authors suggested that regardless of context/population it is common that repairs are not completed, potentially due to lack of wheelchair maintenance training [14].

Kam et al. interviewed eleven prosthetists to examine the environmental and personal factors in low-income countries that influence prosthetic rehabilitation. They found that lack of continuity of care was a problem for their clients: the AT users did not know where to locate services for repair which impeded daily participation, which was also exacerbated by weather and tough terrain [15]. This resulted in recommendations on more durable devices, to better suit the environments they are used in [15]. Loeb and Eide found that 7% of assistive device repairs are done by government services, while 40% are maintained by the users or their families. 40% of devices were not maintained or repaired, because of lack of money among other reasons [16]. Wyss et al. investigated priorities in lower-limb prosthetic service delivery based on an international survey of prosthetists in low and high-income countries, finding durability and repairability of prosthetic feet and knees are particularly important [17]. A cross sectional study into mobility & satisfaction with lower-limb prosthetics & orthotics users in Sierra Leone, found that while 86% were in use, 50% needed repair, and 45% could not pay the costs related to receiving or repairing the assistive device [18]. When participants were asked to choose what they considered to be the three most important items - they reported that provision of follow-up services was most important, followed by access to repairs & servicing and comfort. The same research team conducted a parallel study in Malawi [17], finding similar results, with access to repairs & servicing being deemed most important, followed by durability & follow-up services. In Malawi, they also found that lack of finances to pay for transport was a barrier to accessing the prosthetic and orthotic centres [19]. In contrast in Tanzania, from the rATA [20] conducted, the majority of respondents were satisfied or very satisfied with the maintenance and repair services (68%) [21]. Overall though it is clear that there is a need for local repair of assistive devices it is not being met [22].

Borg et al. found that assistive technology services are often in short supply and located far from the population in need, meaning repair at specialist workshops is often simply not an option [23]. While specialist repair services exist for assistive products, UNICEF found that in developing countries 28% of respondents reported that specialist repair services were not available at all, and 47% reported that only limited repair services were available [1]. The study showed that only a minority (25%) reported that these repair services were available, compared to the 62% in high income countries [1]. There is a view that community-based approaches might be a better route to achieve AT access in these geographies. Mater et al. did a comprehensive scoping review of assistive technology and two of their key findings were that taking a systems approach could help improve access to affordable assistive technologies and that community-based approaches may be a way to enable underserved groups to access assistive technologies and their repair [24]. The potential for improved access through optimizing these existing third-party repair services has not fully explored, nor how to facilitate this in the design, manufacture and provision of assistive products and services.

A few contributing factors exacerbate gaps in AT provision. Funding is a common problem, with the lack of planning and funding for follow-up services such as maintenance, repairs and spare parts being a barrier to sustained use of assistive products [21]. The provision of the AT device may have occurred at a one-off event through donation or received at temporary camps - this does not lend itself to integrated follow-up services. For wheelchairs, various studies point to provision across low-middle income countries being over-reliant on donated and inappropriate products that are distributed without input from trained personnel [1,25,26]. Similarly, Kenney et al. found a high degree of reliance on donations of prostheses in some centres in Uganda [27]. In these cases the user could have travelled great distances to this centralized location and have no contact with trained professionals after returning home. Any follow up is hard to achieve with these situations, therefore a repair service is often not available. This aspect of patient travel is ubiquitous and creates great difficulty in implementing effective follow up services. For example in some countries most potential users reported travelling up to 25 km to access assistive products, with more than one in five users travelling more than 100 km [21]. Alternatively the user may have obtained the device from a local clinic which simply does not have the resources for adequate continual care and monitoring [27].

The lack of longer-term outcome tracking and studies are another unhelpful factor. Data is often not collected beyond first provision, and impact is displayed only in numbers of devices handed out [28,29]. This means that issues around repair and maintenance, and whether a device is used beyond the short term, become invisible to decision makers and therefore continue to not be addressed

In high income settings, a wider range of dedicated research studies can be found showing variation in the effectiveness of AT repair services. In the USA multiple studies show the effect of repair and maintenance on injury levels. For example Hansen et al. show the importance of active check-ups and maintenance for users (N = 253) in decreasing the rate of accidents [30]. Maclure et al. found various negative influences on a person's life, suggesting changes in insurance reimbursement policy, and patient and clinician education are necessary to reduce the number of repairs and adverse consequences that occur. Worobey et al. review the factors influencing these issues, and highlight the need for higher standards, access to guicker service, and better training of users on wheelchair maintenance and repair [31,32]. Henderson et al. looked at the consequence of repairs on veteran users specifically, highlighting the need for preventative maintenance and time efficient approaches for repair, to avoid negative outcomes.

For prostheses, various data sources exist on repair in the USA. Participants from the Lower Extremity Assessment Project (LEAP) reported purchasing a new lower limb device every 2.3 years [33]. Self-reported data regarding upper limb prosthetics replacement rates range from one year to five years between replacements [34,35]. Etter et al. explored prescription and repair rates of prosthetic limbs in the Department of Veteran Affairs (VA) healthcare system [36]. They showed the typical costs associated with these services exceed the funding provided by most insurance plans, and this likely limits access to needed devices [36]. A wheelchair repair registry has also been developed in the USA, documenting rates of repair and maintenance issues, enabling better accountability and planning of services [37,38].

In Ireland participants in a 2020 study described specific problems with accountability in terms of repair and maintenance in wheelchair and seating service provision [39]. They found that health service funding often did not apply to repair, and when it did, there were problems with the accountability of the thirdparty services tasked with it, with long wait times for repair being common. Participants described completing repair themselves, paying privately for repairs, or using community wheelchair organizations [39]. Gowran et al. similarly describe these problems in Ireland from a much larger scale survey with some participants describing fixing the wheelchair themselves or at bike shops rather than relying on a service appointment [40].

The Norwegian Assistive Technology Provision Model is includes refurbishment and repair as central to its business model. People with disabilities in Norway are assessed and provided with AT devices that will be loaned to them for as long as they need them [41]. Once the user has no more need for the AT device, it can be returned to the same centre which will proceed to repair and refurbish it before loaning it to another potential user. Thanks to the effectiveness of this scheme, approximately a third of AT devices provided in Norway are actually reused [2].

Reflecting on the described literature available, this paper highlights the paramount importance of community-based repair for enabling continued access and use of assistive products. These "informal actions" will continue to occur with or without the support of the formal provision system. Our aim is to advocate for the increased inclusion, support and incorporation of these community-based services into formal provision models.

# A brief note on global repair movements

The "Right to Repair" campaign is a growing alliance of citizens and community groups campaigning for products which are easy to repair and made more durable and more sustainable by doing so [42]. The European Union and the UK have brought in Right to Repair legislation, which require manufacturers of some products (e.g., washing machines,.) to make spare parts available for 10 years, and at a reasonable cost [10,11]. Similar regulations are being passed in the USA [43]. This legislation is designed to influence decisions made at the design stage of a product which have knock on effect on whether a product can later be repaired, maintained and reused. This applies equally to AT, although at present there is no Right to Repair for AT.

These new laws are aimed at high income countries where disposability and the accumulation of WEEE waste have reached high levels. The design implications are just as relevant to low resource settings. Although the environmental responsibility should not be placed at the door of the poorest consumers, Khavul & Bruton argue that "for those living at the bottom of the economic ladder in developing countries, sustainability enhancing innovations can resolve the logiam at the intersection of sustainability, poverty, and the environment. However, for such innovations to stick, they need to be designed with local customers, networks, and business ecosystems in mind" [44,45].

#### Aims & methods

We aim to synthesize relevant aspects of a series of studies carried out as part of larger programmes of work (AT2030 and Fitfor-Purpose prosthetics), in order to understand the place that community-based repair has, and how it could be better incorporated into formal provision models. First, we isolated data on AT repair practices in Kenya, Uganda, Sierra Leone, Indonesia from recent studies conducted in these locations. A group of four researchers with at least one original researcher from each study, analysed the data as a group to identify common themes across the studies, recognizing that not all studies contribute to each theme. A summary of the studies are as follows, with the results found in the next section (Table 1).

#### **Studies**

# Kibera, Kenya – wheelchair users [46]

Kibera is the largest informal settlement in Nairobi and one of the largest in Africa. It covers an area of 2.5 square kilometres, which is now all owned by the Kenyan government. The Kenyan government estimates the total population to be around 200,000 [51]. UN-Habitat suggests the total Kibera population may be much higher between 350,000 to one million, while the International Housing Coalition gives an estimate of more than half a million people [52]. Kibera lacks many basic services such as drainage systems, water facilities and access to electricity. It also suffers from high crime rates and severe pollution [52].

The study participants were people with mobility impairments living in Kibera. To qualify for participation, participants were required to be a wheelchair or tricycle user and have experience of using a mobile phone. Eight participants (four females & four males) were recruited in this study aged between 30 and 63. Among these eight participants, four participants were either born with a mobility impairment which affected both their legs (P01 and P04) or they acquired it at a very young age due to polio (P07), or another condition (P02). P03 and P05 acquired thoracic spinal damage later in life as a result of an accident and

Table 1. A summary of the studies conducted in this work showing the different countries, Contexts, types of at, data collection methods and types and number of

Location / Country	Context	Types of AT used	Data collection method	Participants
Kibera, Kenya [46]	Informal Settlement	Wheelchairs	Semi-structured interview	8 wheelchair users (4 females & 4 males) aged between 30 and 63 designated P01-P08
Bo & Freetown, Sierra Leone [47,48]	Country wide	Multiple	Focus group discussions (FGDs) with a range of AT users; interviews with government agencies working in the AT sector, organizations (DPOs) and private (formal and informal sector) AT providers and service providers; a sample survey of AT users in four low income urban settlements, using an adapted version of the WHO Rapid Assistive Technology Appraisal (rATA) tool	50 AT users involved in FGDs or interviews 23 organizations involved in AT provision and services interviewed 2076 respondents to the rATA survey
Banjarmasin, Jakarta, Solo & Yogyakarta Indonesia [48,49]	Country wide	Multiple	see above	43 AT users involved in FGDs or interviews 26 organizations involved in AT provision or services interviewed 2046 respondents to rATA survey
Kampala, and Fort Portal Uganda [27,50]	3 locations in country (2 x Kampala, 1 X Fort Portal)	Lower and Upper limb prosthetics	Semi-structured interview	13 prosthesis users (female: 7, male: 6, age: 22–48 years) with upper and/or lower limb amputations. Also discussions with 8 technicians working at the 3 locations.

P06 underwent amputation due to vascular issues. Two participants were tricycle users and the other six were wheelchair users. Six participants were mobile phone owners, whereas two had access to a shared mobile phone through a member of the family. The overall aim of this study was to understand the experiences of users of digital and physical assistive technologies in an informal settlement.

In this qualitative study, we collected data both through semistructured interviews and ethnographic observations in the community. The majority of participants (seven out of eight) felt more comfortable being interviewed in Swahili rather than English, which was facilitated by a local guide and a researcher from the University of Nairobi. The anonymized transcribed responses of the eight participants are referred to in the text as participants P01-P08.

# Sierra Leone & Indonesia - users of a range of at devices [47-49]

The research in Indonesia and Sierra Leone was conducted to better understand existing practices of AT provision through informal markets and social institutions. Data was collected through: focus group discussions (FGDs) with a range of AT users; interviews with government agencies working in the AT sector, organizations (DPOs) and private (formal and informal sector) AT providers and service providers, and; a sample survey of AT users in four low income urban settlements, using an adapted version of the WHO Rapid Assistive Technology Appraisal (rATA) tool [20] covering around 2000 respondents in each country. The interviews and surveys were conducted in the local languages of Krio (in Sierra Leone) and Banjar & Bahasa Indonesia (in Indonesia), and then translated/transcribed for analysis. Both the qualitative methods with AT users and the rATA survey included questions related to AT services including repair. Fieldwork in Indonesia conducted in the cities of Banjarmasin, Jakarta, Solo and Yogyakarta, and in Sierra Leone in the cities of Bo and Freetown.

# Uganda – lower & upper limb prosthesis users [27,50]

The research in Uganda was conducted with the charity Knowledge for Change, as part of the Fit-for-Purpose project, which aims to design and test low-cost, high quality, purely mechanical prostheses, suitable for low resource settings, using locally available resources for manufacture, fitting, and evaluation [27]. The aim of this exploratory study was to identify common failures of prosthetics in Uganda, and to investigate how prosthesis users get their prosthesis repaired when it fails.

This study visited three orthopaedic workshops to interview orthopaedic technologists and prosthesis users: (1) Mulago National Referral hospital in Kampala, the largest public hospital in Uganda; (2) Fort Portal Regional Referral Hospital, a public hospital in Western Uganda; and (3) Katalemwa Cheshire Home for Rehabilitation Services, an NGO in Kampala specializing in rehabilitation for children with disabilities.

Most of the patients interviewed required a prosthesis following a traumatic injury. They were therefore referred to the prosthetic workshop by the hospital where they had been treated for that injury. Despite healthcare being free at the point of care in Uganda, due to lack of government funding for components or materials, patients typically pay to receive a prosthesis. The costs are negotiated with the patient depending on the materials and components required, and if the patient is unable to meet the costs they will not receive a prosthesis. Occasionally when the workshops receive donations, prosthetics can be provided for free however these may not be appropriate for the specific needs of the patients. The provision process is therefore ad-hoc, depending on what patients can afford and the materials available at the time.

Semi-structured interviews were conducted using interview guides with 13 prosthesis users (female: seven, male: six, age: 22-48 years) with upper and/or lower limb amputations. The study participants were all experienced prosthesis users (prosthetic use range 4-29 years). The study participants were chosen by the orthopaedic technologists given the following criteria: (1) had an upper or lower limb prosthesis; (2) had not been interviewed previously as part of the Fit-for Purpose project; (3) lived a commutable distance from the workshop; (4) had a contact telephone number on file. Five interviews were conducted in English, and eight interviews were conducted in Luganda with support from a translator, with transcription into English for analysis.

#### Results

We identified six themes of interest across the studies. Not all studies contribute to each section of results and we have indicated which studies have data on each theme after the subsection title. The amount of data found in each study across these themes largely dictates the level of discussion we have for each of these.

Firstly, we wanted to learn about the experiences of users with broken devices that were found across locations and device types, and what impact breakages have on users when they occur, as well as how often repairs are needed. These are discussed in Experiences of Breakages & Frequencies of Repair and Impact of Broken Devices.

Next we wanted to examine some of the different models by which repair occurs in the studies. These are grouped into three sections:

# Individual or informal repair in the community

Where either the AT user themselves repaired the device or they individually sought repair via an array of informal tradespeople in the community. We found that this was the primary method of repair, except for prosthetics where there was stronger emphasis on finding the required specialism.

# Local initiatives

Where repair and maintenance was facilitated by a group approach such as through a local DPO, or through a semi-formal service aimed specifically at addressing the needs of AT users.

#### Specialist AT workshop repair

Where repair was done by a specialist at the clinic that provided or does provide AT.

Finally, in Problems & Concerns with Repair – we give results for where participants in the studies highlighted problems they found with the available model of repair and concerns that they had, both with the repair, but also with the outcome that the repair had on their lives.

#### Results

# Experiences of breakages & frequencies of repair (Kenya, Uganda)

The wheelchair users in the Kibera study all required a multitude of repairs to keep them working, and generally the condition of the wheelchairs seen was poor. Most wheelchairs used in Kibera required some form of repair within a year, and all participants reported that they usually had major repairs (e.g., welding) done at least three to five times before the chair was no longer viable. From the interviews of just eight participants, nearly every part of the wheelchair was given as examples of what has been broken. Most failures rendered the wheelchair non-functional. The most common repair was welding the main frame of the wheelchair together. If the wheels get broken, generally these must be replaced rather than repaired, and can be if the wheelchair is compatible with common bicycle wheels. Punctures are easily repaired for minimal cost. The fabric and plastic seating is not easily repaired and a seating failure could mean that the wheelchair is no longer useful.

In the Ugandan study 11 out of 13 interviewees had experienced at least one failure of their prosthesis, with four experiencing three or more separate failures. Failures of prostheses were addressed in one of four ways: (1) returning to the original workshop where their prosthesis was provisioned; (2) going to a local tradesperson, such as a mechanic; (3) completing the repair themselves; or (4) not getting the prosthesis repaired.

The most common failures for lower limb prosthetics were of the prosthetic foot, usually either breaking around the metatarsophalangeal joint or the keel becoming loose. These failures are usually not repairable so the foot is replaced. When a shank component or knee joint breaks these can sometimes be reinforced or welded if a replacement is not available. Simple failures such as loose bolts or damage to the covering are usually repaired quickly, and if the socket no longer fits, technicians often try making adjustments, for example to the padding, instead of moulding a new socket.

For upper limb prosthetics, the most common failures were of components that typically fail due to wear and tear such as the cosmetic gloves, harness or suspension belt, and cables or joints if included. These are usually replaced rather than repaired. The harness and cable can be easily replaced as the materials are readily available, however the elbow joint and cosmetic glove are much harder to source.

#### Impact of broken devices (Kenya, Uganda)

In Kibera, the impact of having a broken wheelchair was considerable across all participants. They were generally immobile for the duration and required assistance from friends or family to get the repair done. Toilets, for example, are communal in Kibera, so they would not be able to get themselves there. For example, P01 stated "If it is spoilt it affects a lot because it means I can't move." And P02-P07 reinforced this stating, "Maybe I just sit down." (PO2); "If it breaks down it can be very hard for me and I would face many challenges because it will not be easy to go to anywhere and even to go to the toilet that can cause a lot of problems." (PO3); and "I just lay in bed." (PO5). "... if my wheelchair is in good condition, I can receive a phone call that I am required at a certain place, I will just get on to the wheelchair and go, but if the wheelchair is not working I cannot go." (PO6). For P07 who before receiving a wheelchair was able to walk/crawl to some degree on all fours - the use of the wheelchair has meant that he has lost this ability and now relies on the wheelchair. P07: "Mostly it is the one that helps to go and get materials, but when it is broken down everything stops, it is not only the wheelchair, I cannot go to bring my business materials, I cannot go to the toilet, I cannot go for lunch, I will just sit there, I will just sit indoor whole morning till night, so when it breaks down I experience challenges."

P04 who has the ability to walk to some degree using crutches also explained the impact when his crutches broke: PO4: "You know if they broke down, there is no way they can be repaired, they break in the middle -half way, sometimes I was walking at the stage of Olympic, I was going somewhere, I was walking slowly as I moving away for the vehicle, a drunkard man with a vehicle hit me, one crutch broke there and then, blood was coming from my hands and I could not see, I did not know what to do, if it was not for my mother, I would have been hurt, so the crutch got spoiled and could not be done welding because it broke, its end bent and could not be taken for welding, so I had to walk with my knees as I waited to get other ones."

In Uganda, almost all of those interviewed mentioned difficulties getting jobs due to discrimination, although nine of the 13 were employed when we interviewed them. Of the four who were unemployed, this included two of the three with upper limb amputations. Most of the participants reported that they would be unable to work when their prosthesis was broken.

As well as prejudices against them, accessibility in Uganda is very challenging, and there is very little infrastructure to support people with disabilities. Roads and walkways are busy and poorly maintained, public transport is not well designed for people with disabilities, and very few homes are adapted for people with mobility impairments. This is difficult for people even with their prosthetic, but without them, transport may not be possible and even getting around their home safely may be challenging. This would likely have a severe impact on their quality of life and their psycho-social wellbeing.

# Individual or informal repair in the community (Kenya, Sierra Leone & Indonesia)

In Kibera, repairs were almost all achieved via the tradespeople present in the local community - most commonly welders with specialist knowledge of other applications, and in particular bicycle repair workers. To note, occupations based around the repair or re-use of goods are common in Kibera. There was widespread agreement in the interviews that if repair was not possible the device was abandoned. Only participant P01 reported making minor repairs on his wheelchair himself:

P01: "The metal rods do break and that you take to the welder to weld, its wire can come off and that one you have to take to the technician, but if it is just a puncture, I do it myself"

Some breaks were so anticipated by the participant, that when they received a new device, they went straight to the welder and had the weak spot reinforced. For instance:

P07: "There is a place I have identified and even if I buy a new one, since I know the particular spot where it spoils I will take it there to make some reinforcement, the metal is welded to avoid bending."

I: "Okay, even before it breaks down?"

P07: "Yes, and if it breaks down you will be required to put the metal, under my seat, there is a metal that I put myself because you know if it hits the pavement it bends, so the metal protects it from bending."

Participant P01 highlighted the robustness of designs that use common fasteners:

I: "How many times have you taken it for repairs?"

P01: "It is how many times... four times, and has happened when you are using it and some parts break so you take it for welding. But if it is the type with bolts and nuts they don't break easily but this welded one

The possibility of repair was limited by the knowledge of the available tradespeople, so some components have to be replaced instead of repaired, however this might not be the case in a better resourced setting:

P02 (referring to wheels): "If they break down they don't have to fix it because they don't know how to fix them."

I: "So if the bearing of the axle breaks of the wheel you can't fix?"

P02: "Yes"

I: "So if the wheels are broken you can't fix in Kibera?"

P02: "You just buy another one because we don't know anywhere to fix the wheels'

Costs of repairs varied greatly. This was not just due to differing parts, similar jobs cost widely differing amounts. They usually ranged from 200 to 2000 KES, with P02 stating that they had paid 5000 KES in the past. Considering the frequency of major repairs this is a significant portion of the income of the users. The average income in Kibera is 3977 KES per person per month, and it is assumed the actual income of people with disabilities will be much lower than this average.

In both Indonesia and Sierra Leone, individual low income AT users who attended the focus group discussions explained that they routinely repaired their assistive products themselves, or using tradespeople who were not specialized in assistive products (carpenters, welders, and car mechanics). The most commonly mentioned repairs to assistive products were replacing the rubber feet of crutches and sticks, as these wear down quickly and lead to dangerous instability for users. These repairs were often done by AT users themselves or by local tradesmen (often car mechanics) and were typically made using rubber from car tires.

The importance of repair of crutches is shown by an interview with a participant from Freetown, Sierra Leone, referred to as B. He had his left leg amputated in the 1990s during Sierra Leone's civil war. B was trained to use elbow crutches while undergoing rehabilitation. Despite being fitted and trained to use a prosthetic leg, he developed blisters on the stump and found moving around easier without the prosthesis, which he therefore stopped using. B has gone through many pairs of crutches, some of which he was given, and others which he has bought from second-hand shops and people he knows - negotiating down to 50,000 SLL (around US\$5) for a pair. He is currently the captain of the Sierra Leone amputee football team. In order to play football comfortably, he has adapted his crutches, stitching the elbow grip shut with metal wiring so that the crutches do not fall off when he raises his arms. He regularly replaces the rubber tips of his crutches - which he explains are the first to deteriorate, followed by the crutches' metal foot. He purchases replacement tips made of rubber from car tires at garages and workshops, describing them as significantly more durable than the originals. He relies primarily on his veteran's pension as income, and is unable to afford most costly assistive products and associated services.

In Indonesia, where a wider range of assistive products are available than in Sierra Leone, participants also frequently discussed repairing other assistive products including wheelchairs, and folding canes for the blind. In these cases of individual repairs the knowledge was based largely on individual users' experiences either in doing repairs themselves, or instructing tradespeople - although in Indonesia some AT users had obtained information from social media groups of DPOs such as Pertuni Banjarmasin Beriman (a DPO for those with visual impairments) or from YouTube tutorials.

## Local initiatives (Sierra Leone, Indonesia, Uganda)

In Indonesia and Sierra Leone, DPOs had acted as a base for a more collective approach to repair of assistive products. For example in Sierra Leone, the DPO "Handicap Action Movement" in Freetown and the Disability Rights Movement in Bo, are largely constituted of people with disabilities who have, over time, learnt how to assemble and repair both wheelchairs and PETs (Personal Energy Transportation Carts), as well as how to produce rubber tips to repair crutches and now provide these (at a fee) to AT users. In Indonesia the knowledge base and collective capacity for DPOs repairing assistive products is more advanced. For example, in Central Java and Yogyakarta provinces the NGO United Cerebral Palsy - Wheels for Humanity (UCP), have trained around 70 people (80% of whom are people with disabilities) in wheelchair repairs and have supported them in setting up workshops. While these workshops are unlicensed, because the parent NGO UCP has an MoU with the Provincial government, they are able to provide state subsidized repair services to wheelchair users. The NGO "Yakkum" has a similar MoU arrangement with Yogyakarta provincial government regarding repairs to prosthetics and orthotics.

In Uganda, the workshop at Katalemwa had trained satellite repair technicians, some of them ex-patients of Katalemwa, to be able to complete simple prosthetic and orthotic repairs without requiring a specialist workshop. These technicians were distributed around the country, and if a patient required a simple repair, Katalemwa advised them to see one of their local satellite technicians. The metal workshop, who primarily serviced and provisioned wheelchairs at Mulago, also provided training in other regions in Uganda on how to conduct minor repairs. They typically train 10-20 people in a region and look to recruit people who already have some trade skills such as welders and mechanics.

In Kibera, although much of the provision of wheelchairs was organized through local DPOs, there were no initiatives concerning repair and maintenance discussed. Participants did however talk highly of the emotional support received by the local DPO groups and the regular meetings made them feel less alone. It is very possible technical issues around devices are also discussed at these meetings, and informal advice between users is given, however this was not mentioned.

# Specialist at workshop repair (Sierra Leone, Uganda)

In Sierra Leone P&O users who had been provided with assistive products by the National Rehabilitation Centre (NRC) told us that they had brought their assistive products back to the centre for repairs. However one wheelchair user also told us that she does not take her wheelchair to the NRC for repairs because public transport providers will not allow her to bring her wheelchair into mini-buses and it would take her more than two hours to reach the NRC on her wheelchair.

In Uganda, all but two of the thirteen interviewed had returned to the original workshop for at least one repair. However, this may not be representative of prosthesis users in general, as all those interviewed lived near the workshop. The average travel time to the workshop of those interviewed was 63 min (range five minutes – two hours).

A note on patient travel - a recent retrospective study of amputees in the Acholi region of Northern Uganda, a region with poor transport infrastructure, found the average distance from patient's homes to the referral hospital where they were treated was 91 km [53]. This may mean that those who live further away are more likely to visit local tradespeople for repairs or attempt to repair the prosthetic themselves.

In the Kibera study, no participants were able to access any AT specific expertise for the repair of their devices.

# Problems & concerns with repair (Kenya, Uganda)

Although often local tradespeople are often highly skilled workers, as they do not know the devices well, the repairs varied in quality as reported by the participants in Kibera. This leads to distrust in the repaired device by the users for example P06 was particularly disheartened by previous bad repairs, leading to much reduced use of the device .e.g., "this one has a problem, the way it was welded, some people when they weld they don't do it well and when it I pushed you find there is a problem"

From the participant's perspective in Uganda, their biggest concern about repairs was cost, with many of them struggling to pay for transport to the workshop, even if the repair itself was free. We were told that basic adjustments and repairs could be completed for free, but if new materials or components were required, the patients would have to pay for them. Unfortunately the challenges with sourcing components in Uganda translate into high costs which are often unaffordable to clients.

In Uganda, six of the 11 participants needing repairs had to pay for at least one of them. The repair process was also potentially very time consuming, requiring multiple visits to the clinical centres, with no guarantee of a positive outcome for the patient. This contributed towards patient's reluctance to attempt to get their prosthesis repaired, as they reported they were hesitant to pay for travel if they were not sure it would result in getting their prosthesis repaired.

Another key issue was that the patients appeared to be given inconsistent advice on how to maintain and repair their prosthetic and no follow up appointments were arranged after handover. The metal workshop at Mulago provided wheelchair user manual booklets to patients at handover, but this did not appear to be done by any of the prosthetics and orthotics workshops. One of the participants was not using their prosthetic because the joint had come loose and they were unaware that the workshop might be able to fix it for free.

Many of those interviewed did little or no maintenance of their prosthesis and only two had attempted a repair themselves. Technologists did not appear to encourage patients to seek others to do maintenance or repairs, as they feared that people without specialist training would be unable to repair prostheses safely. Many of the participants had not considered going to somewhere other than the workshop their prosthesis had come from for repairs and were unaware that this could be an option.

#### Discussion

In many high income countries, repair is an expected part of AT services, and although there are issues and gaps in service highlighted in the literature, and varying levels of informal repair occurs - it is still generally backed up by well-resourced and experienced AT specialists with access to parts and equipment. This is not the case in low resource settings. The increased rates of injury associated with inadequate repair and maintenance schedules that are well documented in high income settings, are assumed to be equally true or likely worse. The wear and damage to an AT device is likely to be worse than in high resource settings, exacerbated by inappropriate designs and lower quality available products. Additionally their production usually takes place overseas, leading to parts that cannot be replaced locally, or with little or no stable supply chains - all making repair and maintenance more challenging.

We see from our studies some of the consequences from lack of repair such as AT users being unable to work or shop, cook or even go to the toilet. Repair unfortunately often results in a

degrading of the device, and the user may not be able to trust in the device anymore. Ultimately, this will often lead to device abandonment, and a lack of trust in the fruitfulness of seeking out assistive products in the future.

The majority of repairs were found to be done within the community by the users themselves or by local informal tradespeople with limited or no specialist knowledge. An enabling factor in this, is the strong individual and community ethos of repair and value retention that these communities have through necessity. This ethos is much less present in high income countries, however the climate crisis is bringing it back into view - this time through environmental necessity rather than individual necessity. In either context, very few assistive devices across domains are constructed with this community aspect in mind.

Some approaches might be making reapir problems worse. When projects utilize donated western devices, their complexity can predispose them to require regular repair and replacement [54,55]. It is difficult to refuse free devices even when they are not appropriate to the context. This creates a false economy, however, as there is even less likelihood the expertise to repair such devices is available, and the supply is not reliable enough to offer a sustainable service [55]. Fragmented services, with a lack of government funding, mean individual workshops requiring specialist components may have to import such items. Factors such as import taxes, and multiple organizations throughout the supply chain, can then lead to high prices and barriers to access.

#### Possible routes to improvement

Stakeholders globally who drive innovation of assistive devices have an opportunity in this established community-based repair practice. In its current form, it is merely an inadequate stopgap for these communities who have no other choice. However there is an opportunity for stakeholders further up the value chain to change this. The designers & manufacturers, the investors who fund them, and the policy makers that set targets could recognize that community-based repair can be a beneficial part of the formal model of AT provision. We have shown that the majority of the useful life of the products provided to these users is through this repair & maintenance that is often not a part of the provision plan for these devices. There are multiple avenues by which community-based models of repair could be facilitated, some of which we describe next.

# Repair guides and design that facilitates repair

An obvious drawback of community-based repair is the lack of specialist knowledge of the devices in question. The high potential for inadequate repairs creates distrust in the AT devices, reduced wellbeing of the users, and ultimately abandonment. A possible way to address this is to create specific product (make & model, as opposed to generalized) repair guides for a range of AT devices that could facilitate better repairs via non-specialist workers. These could be produced as third-party documentation, A much better scenario would be manufacturer's themselves producing these documents, with an acceptance that third party repair will occur, along with designs that facilitate this mode of repair. Designs that facilitate non-specialist repair would also optimize this pathway, such as the use of common fasteners and modular designs that could allow part replacement if necessary. Wheelchair designs that align with common bicycle parts have more recently been developed, for example by Motivation, and this model could be used for other AT types.

#### Outcome measures and repair records

A known problem in AT is the lack of data concerning much of the value chain, but in particular what occurs post-provision. Realworld monitoring offers a potentially low-cost method of tracking use, which could be deployable in low resource settings, which Chadwell et al. discuss in their systematic review [56]. A sudden reduction in patterns of use may indicate the need for repair. Repair records are a part of this and if much more holistic data concerning these activities were collected then it could inform the appropriate use of informal repair strategies into formal service design. This goes for both the repair practice and the causality and wider influences on device repair such as Haboubi et al.'s study, which gave indicators to the potential for repair data to inform intelligent provision strategies [57]. Devices could be better chosen based on what their maintenance outcomes are likely to be. With further data and visibility, the important idea that funding of follow-on services are as important an issue as the initial device provision itself might become clear, and without them the real world impact of such funding streams are only a fraction of what they could be.

#### **Ecosystem-led** innovation

Khavul & Bruton argue that introducing innovations without deep customer knowledge, without due regard for the highly networked nature of the local adoption process, and without investment in local ecosystems, will continue to disappoint those interested in harnessing change through innovation in developing countries [44].

We showed clear examples of where the lines were blurred between repair and user-led improvements or adaptations to devices, mostly as a result of experienced use throughout the product life cycle and a resourceful innovative attitude. In Kibera, P07 discussed reinforcing his tricvcle's cross bar on receiving a new one, as he expected it to break based on previously having used the same model. In Sierra Leone, B made specific alterations to his crutches to improve their usefulness and managed the replacement of parts himself. These user-led responses to the current design of the received devices could be leading to improved designs, helping users of similar device models around the world. If further links can be established between manufacturer and repairer - be it the user or an employed tradesperson - then these could be translated into improved, more durable or more repairable designs.

# Community based training, satellite repair workers and outreach services

In Sierra Leone, some knowledge dissemination had occurred through DPOs, and much more established training of wheelchair repair had occurred in Indonesia. There has been work recently to facilitate maintenance training programs globally, for example [58]. These models are rare across AT but are an important indicator of what could be done to increase product life cycles. In Uganda, the training of satellite workers to repair prosthetics is an exciting model that could be expanded further. In prosthetics particularly there is resistance to non-specialist repair and this is not necessarily unwarranted, as severe injury can occur from these devices if incorrectly fitted, such as through falls. By accepting it as a service resource however, and mapping of what repairs can be done effectively by a non-specialist and what must be done by a specialist, a spectrum of service provision could be created. This could increase efficiency and ultimately reduce the burden on the central P&O workshop, as minor jobs have been task shifted to the community in an appropriate manner, and there



could still be support and oversight by an appropriately qualified team. In Uganda, participants mentioned reluctance to attempt to get repairs done due to cost & travel time, and not being sure they would be able to get something fixed. If the device knowledge was more decentralized, then the decision could be based on the product itself and its usefulness rather than the logistics to make it happen.

#### Conclusion

The assistive technology industry is currently limited and extremely specialized, mostly serving the requirements of highincome settings [7]. The products available and service approach often also follow models that are only really applicable to high income settings. When subsections of that model are transferred to low resource settings, the lack of their paired processes downstream such as repair and maintenance in a well-resourced workshop result in severely under-potentiated efforts. We hope that through the literature and case studies discussed, the paramount importance of community-based repair strategies has been shown, as well as the necessity for them to be fully incorporated and supported by the formal AT provision system, wherever they may be.

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