

Department for International Development



Image: WHO GATE

# SCOPING RESEARCH REPORT ON ASSISTIVE TECHNOLOGY

ON THE ROAD FOR UNIVERSAL ASSISTIVE TECHNOLOGY COVERAGE

PREPARED BY THE GDI HUB & PARTNERS FOR UK DEPARTMENT FOR INTERNATIONAL DEVELOPMENT

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# Acknowledgements

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Most pertinently, our thanks go to AT users and communities themselves – including many of our team – who contributed to our research and our findings.

We hope to work with many of you again in the future to revolutionise access to AT for those that need it the most.

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Department for International Development

### About the GDI Hub

Our vision is to amplify the legacy of the Paralympic Games of 2012 by creating partnerships which enable people and communities to lead new thinking about disability across the world; especially where disability exclusion is compounded by the destructive impacts of poverty.

We do this through three strands of work:

- Delivering exceptional, inter-disciplinary research, teaching and practice;
- Stimulating open-source innovation and inclusive entrepreneurship;
- Building co-creation, participation, and community leadership capacity.

All GDI Hub projects have **Global** impact and application; specifically relate to **Disability**; demonstrate genuine **Innovation**; and build an accessible knowledge and practice **Hub** through open collaboration. With our partners and members, we build cross-disciplinary international collaborations to maximize reach and deliver scalable impact. We **always reinvest our income** in these goals and our assets are legally locked for this purpose.

GDI Hub operates as an academic research centre based in University College London (UCL) within the Here East Campus on the Queen Elizabeth Olympic Park, as well as through a Community Interest Company (a UK non-profit), which was co-founded by Directors, Dr Catherine Holloway (Academic Director); Iain McKinnon (Inclusive Design) and Victoria Austin (Strategy and Partnerships) in 2016, alongside the communities, businesses and institutions based on the Queen Elizabeth Olympic Park in east London.

Lord Chris Holmes of Richmond, multiple gold-medal winning Paralympic swimmer and Chair of the All Party Parliamentary Group on Assistive Technology, is the Chair of the GDI Advisory Board which is made up of disabled people from three continents. Founding partners include: The Mayor of London; UCL; London College of Fashion, Loughborough University in London; the Helen Hamlyn Centre for Design at the Royal College of Art; the V&A Museum; Sadler's Wells theatre, and the people and communities that hosted the games in east London.

GDI Hub is building a movement to accelerate disability innovation for a fairer world. Join us?

# **Executive Summary**

ver one billion people – largely disabled people and older people – are currently in need of Assistive Technology (AT). By 2050, this number is predicted to double.

AT can make the impossible possible for people living with a wide range of impairments, but a lack of access to basic AT – such as eyeglasses, hearing aids, wheelchairs or, increasingly, mobile applications - excludes individuals and reduces their ability to live full, enjoyable, and independent lives. Despite the proven advantages of AT for disabled and older people, their families, and society, there is still a vast and stubborn gap between the need and the supply; currently only 10% of those who need AT currently have access to it.

Used appropriately and delivered with the right services and education in the context of an accessible environment, AT is empowering, costeffective, and vital to meet the growing needs of 21st century populations.

### The report

This Scoping Research Report on Assistive Technology seeks to unpick and understand the multi-layered and multifaceted ways in which economic, social, and political factors interplay and interact to create barriers to AT for those who need it the most.

Through primary and secondary research, we explore the current landscape, the limitations, and current initiatives, ultimately answering the question: "How best should a target intervention around AT sphere affect positive change for poor, disabled and older people in Global South priority countries?".

To understand this question, the research team asked two specific questions:

- 1) What are the barriers which prevent access to AT for the people that need it, with a focus on those living in low resource settings within DFID priority Global South countries?
- 2) How should DFID, in partnership with others best direct its intervention toward overcoming these barriers?

### Findings

Our work reveals that, while levels of AT market development vary across countries, key barriers are common. These barriers can be classified into five main categories related to both supply and demand factors and across the 5Ps of People, Products, Provision, Personnel, and Policy.



*Figure: GATE's five key topics (5P): People, Products, Provision, Personnel and Policy.* 

#### People

#### Need to measure impact

Evidence is a key tool to promote investment, as well as to prioritise interventions.

#### Stigma and discrimination

Although discrimination and stigma are worse for some types of disabilities, they pervade all sectors of the disability community.

#### User-centred design

Products designed with the participation of users are ultimately much better in meeting users' needs; they are used more and abandoned less.

#### Products

#### Affordability, availability, and quality

Affordability, both in terms of the full cost of the product as well as service delivery, was mentioned by all stakeholders as critical to success.

#### Standards needed

The lack of globally accepted specification and standards for AT is a significant barrier to the access of effective and appropriate AT.

#### Need for a critical mass of innovation

There is need to open channels for collaborative innovation, as most AT is designed, developed, and sold by large, private companies.

#### Provision

#### Need for sustainable approach

Providing a person with an AT is not a "one-off" occurrence; rather, it is an end-to-end process, beginning with screening activities and encompassing assessment, selection, fitting, user training, follow-up, and maintenance. A sustainable systems approach is therefore essential.

#### Fragmented services

Fragmented, geographically distant service delivery may discourage and even prevent users from accessing services.

#### Donor dependent supply

Donor-dependent supply chains can have a detrimental effect on the continuity and effectiveness of AT provision.

#### Low demand, high cost

Low demand for AT and materials results in much higher cost-per-unit. A globally coordinated effort to bulk purchase, combined with regional distribution hubs, may mitigate the problem.

#### Personnel

#### Expanding current AT workforce

AT service delivery models are dependent on the availability of highly qualified professional staff. Task shifting might be a potential solution.

#### Harnessing the power of technology

Mobile technology is a powerful tool in improving the capacity of personnel involved in AT development and provision, as well as being a mode of new AT delivery.

#### Continued development of workforce

There is need for continued training. One-off training provides little opportunity for follow-up or to further expand knowledge.

#### Policy

#### Lack of coordination

Lack of coordination between parties responsible for the development and delivery of AT results in decreased efficiency of many programmes, with increased cost and an uneven distribution of the AT network across the territory.

#### Policies without implementation

Policies must be implemented and reviewed periodically.

Legislation to facilitate rather than to hinder Excessive bureaucracy can become a significant barrier to the development and delivery of AT.

#### Funding clarity

A more effectively managed funding system, which is clear and transparent for all parties involved, is essential.

#### Other

#### Need for an accessible environment

Access to AT is not a sufficient condition for independence. An inaccessible environment can prevent or limit the use of AT.

# Recommendations for intervention

There is a real opportunity to show leadership on the AT agenda, but a global approach is needed to deliver genuinely revolutionary change.

The way in which this is done matters. The approach to AT provision requires an explicit normative framework; this report suggests this be framed around the following principles:

### A Social Development approach and political leadership

The priorities for intervention should lead to better outcomes for AT users.

#### A global, mission-led partnership

This partnership should go beyond a donor-led approach, with targets well understood by stakeholders, measurable outcomes, and clarity of how to return on investment.

### Testing and piloting market shaping as a methodology

The opportunity to back this approach at scale is still some way off. Global leaders beyond the disability sector should spearhead this work, developing, trialling, and refining a research base.

### Backing market shaping with work on systemic interventions

Work done to reduce the cost of AT must be carried out in conjunction with national governments, with clear routes for the provision of AT within healthcare, education, and other nationally delivered systems.

#### Harnessing innovation

With a focus on leapfrog technology, looking beyond the traditional understanding of products or services, and bringing in fresh players and approaches.

### Community participation and capacity building

The exclusion of AT users from programme design, policy and decision-making leads to less good outcomes, continued power imbalance and political exclusion. An AT 'solution' must be designed to counter this, through building on community-led solutions with AT users involved at every level of the process.

### Conclusions

The challenge of AT is a complex web of market and system failure, compounded by a lack of participation from those that have the best knowledge of the issues (users themselves). This results in a supply/demand mismatch affecting almost a billion people, making AT access one of the most pressing issues facing those that wish to see implementation of the SDGs by 2030.

Any intervention that is to be successful must go hand in hand with policies and practices to remove stigma and discrimination and empower AT users to take part at all levels of society. If the global community can get behind a single mission, enabling an environment where the holistic nature of the problem is acknowledged, innovation can thrive, and there is a willingness to fund large-scale strategic interventions based on what is shown to work, then there is much hope for success.

The risk is that the challenge of AT is complex and multi-faceted and has been largely obscured from view. The expertise needed to tackle the problem from its multiple angles is not held in one place; rather, it lies between the traditional boundaries of innovation, development, disability, and market leaders. Creative partnerships of emerging and established actors, involving AT users and those running the systems that serve them at all levels, will be critical for success.

# Foreword

#### By Lord Chris Holmes of Richmond, GDI Hub Chair

his report seeks to contribute to a better understanding of the issues around access to assistive technology in a global context. Utilising both primary and secondary research, various barriers to assistive technology have been identified and explored. Building on this work and developing opportunities and ways to overcome those barriers is a key part of this project.

The ultimate goal must be ensuring that nobody is denied access to potentially lifechanging products and services.

Assistive technology covers a vast range of tools and products including (but not limited to): walking sticks, wheelchairs, hearing aids, eyeglasses and, increasingly, mobile, and digital applications; essentially, anything that enables people to participate fully and lead more productive and enjoyable lives. I am a proud user of several assistive technologies and am genuinely excited by the mainstreaming of accessibility features in modern technology that is doing so much to bring assistive technology to increasingly large numbers of people.

The fact remains however, that in the global south – where it is estimated that 80% of disabled people live – being able to access appropriate, safe and affordable assistive technology can literally make the difference between life and death. Often simple and relatively cheap products are simply not available. This mismatch in demand and supply suggests that the markets for assistive technology are not operating effectively, which has resulted in assistive products being either too expensive or simply unavailable. Coordinated market shaping activities have worked well for other areas of lifesaving healthcare commodities, for instance bed nets for Malaria, vaccines, and medicines for conditions such as HIV, and contraception. Such activities have not yet been tested for assistive technology.

GDI Hub has produced this report with support from leading market shaping experts at the Clinton Health Access Initiative (CHAI) as well as specialist input from Leonard Cheshire and 'deep-dive' support from Motivation in the UK and Kenya. We would like to thank all these contributors. We would also like to thank the team at the Boston Consulting Group (BCG) who led an aligned piece of work with a focus on wheelchairs and hearing aids over a similar timescale.

The figures are staggering: it is estimated that by 2050 two billion people would benefit from assistive technology, yet 90% will not have access. Assistive technology has the potential to enable and empower and can be a key part of delivering on the United Nations General Assembly's 17 global Sustainable Development Goals. The challenge is huge but the prize, should we succeed, is far more so and we hope this report will provide a comprehensive starting point from which to achieve universal access to assistive technology globally.

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# Abbreviations

5Ps	Five Barriers: People, Products, Provision, Personnel, and Policy
AAC	Augmentative and Alternative Communication
Amparo	Amparo Prosthetics
AI	Artificial Intelligence
APDK Kenya	Association for the Physically Disabled of Kenya
APL	Assistive Technology Products List, by WHO
APPG	All-Party Parliamentary Group
APS	Assistive Products Service Delivery model, by WHO
АРТ	Assistive Products Training Package, by WHO
AT	Assistive Technology
ATP	Assistive Technology Policy Framework, by WHO
BEAP	Built Environment Access Panel
Benetech	Benetech Software for Social Good
BCG	Boston Consulting Group
CABE	Commission for Architecture and the Built Environment
CADTC	China Assistive Devices and Technology Centre
CHAI	Clinton Health Access Initiative
CLASP	Consolidating Logistics for Assistive Technology Supply and Provision
CWD	Children with disabilities
DFID	Department for International Development
DID	Disability Inclusive Development
DPO	Disabled people's organisations
DPU	Bartlett Development Planning Unit
ESPRC	Engineering and Physical Sciences Research Council
EMX	Enable Makeathon X
GATE	Global Cooperation on Assistive Technology
GAP	Global Assistive Technology Partnership
GCRF	Global Challenge Research Fund

GDI Hub	Global Disability Innovation Hub
GDI Hub CIC	Global Disability Innovation Hub Community Interest Company
GREAT	Global Research, Innovation, and Education in Assistive Technology
GSMA	Global System for Mobile Communications
GSofA	Glasgow School of Art
HHCDesign	Helen Hamlyn Centre for Design
н	Humanity & Inclusion
ICT	Information and Communication Technology
ICRC	International Committee of the Red Cross
IDA	International Disability Alliance
IDIA	International Development Innovation Alliance
IFC	International Finance Corporation
IFPMA	International Federation of Pharmaceutical Manufacturers Associations
IIPP	Institute for Innovation and Public Purpose
IIT Delhi	Indian Institute of Technology
INGO	International non-governmental organisation
IoM	Institute of Making
ISO	International Organization for Standardization
ISPO	International Society for Prosthetics and Orthotics
ISWP	International Society of Wheelchair Professionals
KNOW	Knowledge in Action for Urban Equality
LC	Leonard Cheshire
LCRC	Leonard Cheshire Research Centre
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
LMICs	Low and Middle-Income Countries
LDS	LDS Humanitarian Services
LLDC	London Legacy Development Corporation
LRS	Low resource settings
LSHTM	London School of Hygiene & Tropical Medicine
LUL	Loughborough University London
LCF	London College of Fashion

LV Prasad	L. V. Prasad Eye Institute
MDGs	Millennium Development Goals
MIT	Massachusetts Institute of Technology
Motivation	Motivation International
Motivation Australia	Motivation Australia
Motivation Kenya	Motivation Kenya
МОН	Ministry of Health
MOU	Memorandum of Understanding
NCDP Kenya	National Council for Disabled Persons
NGO	Non-governmental organisation
NORAD	Norwegian Agency for Development Cooperation
OECD	Organisation for Economic Co-operation and Development
Ottobock	Industries Co., Ltd.
Ottobock China	Ottobock Industries China
OU	Open University
PD	Participatory design
РЕЕК	Peek Vision
ProsFit	ProsFit Technologies
RCR	Royal College of Art
RED	Research and Evidence Division
Rehasense	Rehasense Europe
RLEs	Resource-limited environments
R&D	Research and Development
ROI	Return on Investment
SDGs	Sustainable Development Goals
SSI	Swedish Standards Institute
UCD	User-centred design
UCL	University College London
UCLCS	UCL Department of Computer Science
UCLIC	University College London Interaction Centre
UCP Wheels	UCP Wheels for Humanity

UDPK	United Disabled Persons of Kenya
UK	United Kingdom
UN	United Nations
UNICEF	United Nations Children's Emergency Fund
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNPRPD	United National Partnership on the Rights of People with Disabilities
UNSEO	United Nations Special Envoy Office
USAID	United States Agency for International Development
WB	World Bank
Wellcome	Wellcome Trust
WHO	World Health Organization
WR	World Report on Disability (WHO and WB, 2011)
WWI	Whirlwind Wheelchairs International

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Figure 1: WHO

"For most people, technology makes things easier. For people with disabilities, technology makes things possible" Mary Pat Radabaugh

### 1 Introduction

#### 1.1 The scale of the issue

Over one billion people (largely disabled people and older people) are currently in need of Assistive Technology (AT). By 2050 this number is predicted to rise to two billion. AT makes the impossible possible for many. However, without access to AT and an accessible environment in which to use it, disabled<sup>1</sup> and older people are marginalized from their communities (WHO & WB, 2011). A lack of access to basic AT – like eyeglasses, hearing aids, wheelchairs or, increasingly, mobile applications – excludes individuals and reduces their ability to live full, enjoyable, and independent lives, often making serious health problems worse. A lack of AT for those who need it also results in losses for society as a whole, as people who would otherwise be able to contribute economically and socially to their communities are excluded from doing so (WHO & WB, 2011).

Despite the proven advantages of AT for disabled and older people, their families, and society more broadly, there is still a stubborn gap between the need and supply. Only 10% of those who need AT have access to it (WHO, 2017), which makes achievement of the United Nations Sustainable Development Goals (SDGs) highly unlikely, if not impossible.

The lack of availability of AT for the poorest people compounds intransigent poverty in complex and multi-faceted ways. It also affects the effectiveness of almost every development initiative undertaken globally, yet this is rarely recorded or quantified, never mind overtly tackled. Mainstream and

<sup>&</sup>lt;sup>1</sup> 'Disabled People' is the term preferred in the UK by Disabled People's Organisations, rather than the UN favoured 'people/persons with disabilities'. 'Disabled people' is used to refer to the way in which society disables people with impairments, for instance by adding steps to a building, while the latter term implies ownership of the 'problem' by the individual. Throughout this text, the UK approach has been used, recognising that this is contested.

disability-inclusive development initiatives have both largely did not address AT in systematic and sustainable ways.

Large numbers of the people who use AT are disabled people, however, increasingly AT is utilised by the increasing number of older people who need it for everyday tasks. The estimate of the numbers of people that need AT is therefore largely based on global assumptions about the numbers of disabled and older people (WHO & WB, 2011). The increasing number of people who will use AT due to age is an opportunity to make AT more accessible and affordable, however, this should not allow the global community to lose sight of the products and services which should be available to disabled people throughout their lives.

It is well established that poverty and disability are both a cause and consequence of one another (Banks, Kuper, & Polack, 2017). With over 80% of the disabled population now living in low to middleincome countries (LMICs), the issues associated with access to AT are skewed to affect Global South countries more than their northern neighbours. Yet it is precisely in these countries where market and systemic failure compound with extreme poverty to mean that people desperately in need of AT (often including very low-cost items like eyeglasses or walking sticks) frequently receive the wrong items which can increase the likelihood of acquiring additional life-threatening conditions (WHO, 2012), or no AT at all.

The impact of this lack of access is: children left out of education; adults excluded from earning livelihoods; women (particularly but not exclusively) unable to lead independent lives; and older people unable to take part in their communities, as well as serious health problems which can result in premature death (WHO, 2012).

AT, delivered with appropriate services and education, and used appropriately is empowering, costeffective and vital to meet the growing needs of 21st century populations. As such AT is recognized as a key enabler in achieving the SDGs (Tebbutt, Borg, MachLachlan, Khasnabis, & Horvarth, 2016).

In this scoping report we seek to unpick and understand the multi-layered and multifaceted ways in which economic, social, and political factors interplay and interact to create barriers to AT for those who need them the most. It should be read as a first step into answering these complicated questions, which hopefully provides a roadmap to how the global community can begin to work together, in new ways, to bridge the gap to AT. Through primary and secondary research, we explore the current landscape, noting the limitations but also current initiatives, ultimately answering the question: "How best should a target intervention around AT sphere affect positive change for poor, disabled and older people in Global South priority countries?"

#### 1.2 Scope of the research

In March of 2018, GDI Hub CIC, with input from UCL, Leonard Cheshire and Loughborough University, was commissioned by IMC Worldwide (on behalf of DFID) to conduct a scoping review which analysed and synthesised the evidence on AT as technical support ahead of the Global Disability Summit. The research was designed to investigate two questions:

- What are the barriers which prevent access to AT for the people that need it, with a focus on those living in low resource settings within DFID priority Global South countries?
- How should DFID, in partnership with others (including particularly other donors) best direct its intervention toward overcoming these barriers?

#### 1.2.1 Research methodology

The research methodology has been flexible and iterative in nature, bringing in expertise from within DFID, CHAI, GATE at the WHO, LC and Motivation in the UK and Africa as well as expertise and input from local groups and organisations across East Africa. Emerging ideas have been tested through stakeholder interviews and discussions and refined through partner workshops and external events.

The research methodology was designed to enable interactions between stakeholders, to integrate explicit knowledge with tacit knowledge (WHO, 2016) to guide policy development. It was characterised by a participatory and consultative processes; having clear objectives, being inclusive and transparent, providing an opportunity to reflect on the applicability of evidence in different contexts and promoting dialogue among several types of stakeholders.



Figure 2: Research Approach

#### 1.3 Definitions and assumptions

#### 1.3.1 Assistive Technology and Assistive Products

Through the scoping review exercise, we have found that that there are many varied definitions of the phrases assistive technology, assistive products, and assistive devices in use by a wide range of institutions and individuals. For consistency, we use the following definitions:

**Assistive technology**, a subset of health technology, refers to assistive products and related systems and services developed for people to maintain or improve

functioning and thereby promote well-being. It enables people with difficulties in functioning to live healthy, productive, independent, and dignified lives, taking part in education, the labour market and social life. It can reduce the need for formal health and support services, long-term care, and the burden on carers. Without assistive technology, people with disabilities and older people and others in need are often excluded, isolated, and locked into poverty, and the burden of morbidity and disability increases. (WHO, 2018)

**Assistive products** include any external product whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote his or her well-being. They include wheelchairs, hearing aids, walking frames, spectacles, pill organizers and prosthetic legs, as well as assistive information and communication technology such as memory aids, specialized computer hardware and software, augmentative and alternative communication, and customized telephones. Assistive products are essential tools: to compensate for an impairment/a loss of intrinsic capacity, to reduce the consequences of gradual functional decline, to reduce the need for carers, for primary and secondary prevention, and to help to rationalize health and welfare costs. (WHO, 2018)

#### **1.3.2** Definitions of disability and AT users

We recognise that the definition of disability is hugely contested and such discussion as given by (Shakespeare, 2013) and (Oliver, Sapey, & Thomas, 2012) is outside of the scope of this report. However, definitions are important and a brief exploration of who we mean when we speak of disabled people and AT users is needed.

Disability in contemporary society is a complex and widely misunderstood issue, which has a broad structural basis (Slorach, 2016). It is a result of the interplay between the social and biological (Shakespeare, 2013) and its definition is also deeply political and contextual, with society helping to construct, maintain and intensify the effects of impairments, and translating these effects into disablement (Baylies, 2002). A person's own abilities and how they are managed certainly does affect their lives, and sometimes this impact is negative (Shakespeare, 2013), however, this is not the cause of disability. Instead, it is the way we run our society – economically, socially, politically – which reduces the availability of 'the good life' to those living with impairments. It is also critical to acknowledge that given the cultural dimensions of disability, definitions must evolve from the current skew towards Western perspectives which are of limited relevance to poor disabled people in the Global South (Chataika & McKenzie, 2016). Therefore, for the purposes of this report the term "disabled people" stands for people who are excluded from full participation in society due to a lack of systems, products, and services which would mitigate their impairment.

The concept of AT users is in some ways less complex that that of disability. The concept encompasses, predominantly, two sets of people: disabled people and older people (with some people identifying as both older and disabled). This definition is the basis upon which the evidence is calculated in the World Report, though many of the people counted within the report are older people who would not recognise a disability identity at all.

With all of this in mind, within this report, we rely on the understanding that AT is for more people than just those who identify as disabled (as recommended by WHO GATE), but on the basis that we understand that those with impairments constitute a significant percentage of all AT users.

#### 1.4 Structure of the report

The Scoping Research Report has been designed to support policy-making by packaging the research evidence in a way that is accessible, relevant, easy to use and applicable. Efforts have been made to use the best available evidence to clarify the problem and its causes, and to identity and frame policy options to address the problem of lack of access to AT around the world.

This report is organised as follows:

- Section 1 (this section) gives the introduction, scope, and assumptions.
- Section 2 sets out the background evidence and review of the literature, concluding with the Barriers to AT which shape the initial primary research.
- Section 3 presents the primary research (interviews, workshops, and events) and names the key themes for further investigation.
- Section 4 contains the deeper dives into East Africa and Kenya, with a focus on market shaping and innovation (drawing on USAID-funded work and CHAI evidence). The East Africa region was chosen as it contains several DFID priority countries and summit co-hosts Kenya, in particular.
- Section 5 summarises the recommendations for policy makers based on this research.
- Section 6 presents our brief conclusion.
- Appendices present the detailed evidence to support the findings.

'Hopelessness is both the consequence and the cause of inaction or immobilisation; opening spaces to aspire and connect people with hope, is crucial for enhanced mobilisation and change.'

(Freire, 2014)

# 2 Background, context, and secondary literature review

#### 2.1 Introduction to this section

Assistive Technology (AT) is scarce. For the people who need AT to be able to play a full role within their families and communities this scarcity can result in a significant reduction in well-being, as well as challenges to human rights and dignity. Globally, WHO estimate there are 1 billion people who need AT (WHO, 2018), a number predicted to rise to 2 billion by 2050. Depending on geographic location and impairment, a person in need of AT may be much more likely to lead a full life if it is provided, or be subject to a greater likelihood of exclusion and poverty if it isn't (WHO, 2018).

The aim of this section of the report is to review the published literature and background policy and partnerships frameworks, to shine a light on the known barriers to AT provision. We critically summarise several recent review papers around AT as well as Information and Communication Technology (ICT), to inform our understanding of the barriers to AT and shape the primary research.

#### 2.2 Existing global policy frameworks

#### 2.2.1 CRPD

The rights of disabled people were enshrined by the international community when the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol (<u>A/RES/61/106</u>) was adopted on the 13<sup>th</sup> December 2006 (UN General Assembly, 2007). Although the CRPD entitles all people to have access to available and affordable AT and stipulates that States should take effective

measures to enable access to AT – and despite the fact the Convention is now ratified by 177 countries – AT still is a distant dream to many disabled people. Only one in ten have access, and this access is highly skewed to high resource settings (WHO, 2018).

#### 2.2.2 SDGs

However one measures development progress – which is hugely contested – one thing is agreed upon: disabled people are very often amongst the poorest of the poor, no matter what evidence base is used (Banks, Kuper, & Polack, 2017). The current UN Sustainable Development Goals (SDGs), which were launched in 2015, have, for the first time, recognised the rights of disabled people across the 17 goals (Figure 3). They enshrine a commitment to "leave no one behind," a specific reference to disability as well as the beginning of a sign that work for other marginalised groups, for example older people or the LGBTQ community, is needed to move development goals forward.

AT is essential for the realisation of targets within all 17 of the SDGs (Tebbutt, Borg, MachLachlan, Khasnabis, & Horvarth, 2016). Therefore, provision of AT is essential for inclusive, sustainable development; contributing to positive societal, economic, and environmental benefits. This can only be achieved through a coordinated and focused approach, spearheaded by governments and international agencies. As the global number of people needing AT continues to grow, universal, affordable access must be a priority.

Countries are supposed to provide reports against their progress on disability inclusive development, yet these are rare and, where they do exist, poorly scrutinized. One area of reporting for disability which has gained traction within the UN is the short set of questions developed by <u>Washington Group on Disability Statistics</u>. These six questions have helped to standardise how disability is counted, however, it has done so firmly within the health domain, focusing on the presence of impairments even if an AT is present. Therefore, whilst these measurements are important in tracking overall progress of the progress in achieving the SDGs they neither capture who is using AT or the impact (when positive) of AT, nor the need for AT directly.



Figure 3: Sustainable Development Goals

#### 2.2.3 World Report

A dearth of evidence on which to base policy to tackle the issues related to disability was one incentive for the World Health Organisation (WHO) and the World Bank (WB) to combine forces to produce the World Report (WR) on Disability in 2011 (WHO & WB, 2011).

The WR found that disabled people are being prevented from contributing to society, family, and communities. The barriers to inclusion include: inadequate policies and standards; negative attitudes, lack of provision of services (e.g. rehabilitation, health services); poor service delivery when it does

exist; inadequate funding; lack of accessible environments; lack of consultation and involvement and a lack of data and evidence (WHO & WB, 2011).

The WR makes a series of recommendations at the highest level to address the inequality faced by disabled people. This is an excellent starting point and gives us a sense of the numbers of people who may need AT. Under these broad proposals, however, it is necessary to develop specific interventions. The next step would be to build on the general recommendations in the WR and to develop a rigorous framework to ensure that AT was provided to everyone in need of it.

#### 2.3 Existing global partnerships arrangements

#### 2.3.1 GATE – Global Cooperation on Assistive Technology

To address the substantial gap between need and access to AT, WHO established the Global Cooperation on Assistive Health Technology (GATE) initiative in 2014. GATE has been successful in gathering considerable research, evidence, a priority list of products, expertise and practice-based guidance around AT. This work culminated in the 'GREAT' summit in August 2017, where the collective, concluding view of the 200-plus attendees was that now is the time to galvanise action in order to catalyse the dynamic AT landscape; maximising the potential of rapidly developing technology and reshaping the market place to enable more high quality, appropriate, AT reach the people who need it.

The GATE initiative aims to improve access to high-quality, affordable AT for everyone, everywhere. It is a concrete step towards realising the goals of key international strategies, including the CRPD and Sustainable Development Goals (Goal 3 in particular – *Ensure healthy lives and promote well-being for all at all ages*).

The acronym GATE also serves as a reminder that access to AT can 'open the gate' – enabling those who need it to leave their home and participate in society (WHO, 2017). Disabled people could be a driving force for change within their local communities by showing how AT can change lives, by helping to improve products and services and by being a voice for the necessary change.

In 2016 GATE released the Priority Assistive Products List (APL; WHO, 2016), which outlines a minimum list of 50 assistive products that are most widely needed, and that national governments should ensure are available to all citizens.

#### 71st World Health Assembly and AT Resolution

On May 25<sup>th</sup> 2018, the World Health Assembly unanimously approved a Resolution calling for Member States "to develop, implement and strengthen policies and programmes, as appropriate, to improve access to assistive technology within universal health and/or social services coverage" (WHO, 2018), as well as to ensure "effective access to high-quality, affordable, assistive products globally." The resolution also calls for Member States to work on research and development, standards and regulations, manufacturing, choice, pricing and reimbursement, procurement and supply, service provision and health emergencies policies related to the improvement of access to AT. The Resolution also requests WHO to prepare a global report by 2021 on access to AT around the world.

#### 2.3.1.1 The GATE thematic research areas

The GATE global priority research agenda for improving access to high-quality affordable AT identified five priority themes:

- 1. Effects, costs and economic impact
- 2. Policies, systems, service provision models and best practices

- 3. Quality and affordability
- 4. Appropriate human resources
- 5. Standards and methodologies for the assessment of need and unmet need.

These themes have been framed within five key topics (5Ps): People, Products, Provision, Personnel

and **P**olicy (Figure 4). There is universal agreement within the GATE community that People, that is, AT users with their families and communities, must be placed at the core of everything that is being done to ensure AT provision, use and impact measurement (WHO, 2017).

These priority areas were recently explored at the GREAT Summit, which resulted in unanimous agreement on the interlinking nature of assistive products and services, the personnel required for AT services, the importance of provision systems, the critical impact of policy, and the central role that users should play at all levels (WHO, 2017).

Following the success of the GREAT summit, a number of papers have recently been published which explore: people (Desmond, et al., 2018), products (Smith, et al., 2018), Policy (MacLachlan, et al., 2018), systems thinking



Figure 4: GATE's five key topics (5P): People, Products, Provision, Personnel and Policy.

as well as the use of the snapshot tool (Layton, Murphy, & Bell, 2018) for capturing and sharing innovation in the AT space. The papers outline the current topic thinking and present recommended actions that are needed to guide and galvanize the collective efforts of all AT stakeholders. These support the WHO AT Resolution Framework (*Figure 5*).



Figure 5: WHO AT Resolution Framework

#### 2.3.2 Addition of "Place" and "Pace"

One of the core debates at the GREAT Summit was the addition of an additional "P" for "Place". This term refers to the often-inaccessible built environments in which assistive products are used, as well as sociocultural contexts of use. Attention to Place is a critical part of appropriate provision:

*"In many cultures, sitting on the floor, kneeling, squatting, walking barefoot, etc. are essential activities of daily living and community engagement... products need to be developed for users* 

taking into account their functional needs, which may be heavily dependent on the physical and cultural environment they live in." (WHO, 2017).

Place also explores the value placed on the management of AT systems and the infrastructures within each country. These are often determined by historical development and understandings within specific contexts (WHO, 2017).

A further theme that emerged related to time or **P**ace. People's needs change over time, both over the course of a day, but also over the course of a lifetime. Therefore, individuals require different products and services depending on their health and ageing trajectory. Another variant is how ready people are to adopt AT into their lives. This interplays with how services are provided (WHO, 2017). Ideally, the service model would cut across the full spectrum of healthcare provision (*Figure 6*). However, this is not always possible and these elements of service – primary, secondary and tertiary – usually develop at difference paces in each country, rarely with good alignment for AT provision.



Figure 6: AT Provision Model: Everyone, Everywhere

This idea of Pace is also one which can reflect ebbs and flows in service, as (for example) waiting times, funding and poor follow-up and repair services can all affect the pace and quality of service provision. This in turn impacts on the fundamental freedoms of people who use the services; however, it also affects the working conditions of personnel, particularly at the grassroots level (WHO, 2017). Finally, Pace covers the fact that communities and national governments are developing and implementing AT services and systems at a varying pace (WHO, 2017).

Whilst the inclusion of Pace and Place were discussed both at the GREAT summit and within the resulting report (WHO, 2017), ultimately, they have been incorporated more broadly into the 5Ps in order to simplify the policy and research framework.

#### 2.3.3 Global health partnerships

#### 2.3.3.1 Global Alliance for Vaccines and Immunization (GAVI)

Created in 2000, the Global Alliance for Vaccines and Immunization (GAVI) is an international coalition that brings together public and private sectors with the shared goal of creating equal access to new and underused vaccines for children living in the poorest countries (GAVI, 2018). GAVI brings together a series of key stakeholders including national governments, international organisations like UNICEF, WHO, and the World Bank, philanthropic institutions, such as the Bill and Melinda Gates Children's Vaccine Program and the Rockefeller Foundation; the private sector, represented by the International

Federation of Pharmaceutical Manufacturers Associations (IFPMA); and research and public health institutions (WHO, 2018).

The Global Fund for Children's Vaccines is a financially independent mechanism designed by the GAVI partners to raise new resources for immunization and swiftly channel them to developing country health systems. The Global Fund makes its funding decisions based on the recommendations of the GAVI Board. Since the partners of the Alliance provide direction and support, administrative costs are kept low – approximately 98% of Global Fund resources go directly to countries (WHO, 2018).

The Global Fund serves as a new experiment in the field of international public health, allowing for prompt and efficient processing of its resources and reaching out to children who are currently being overlooked in more traditional immunization efforts.

The GAVI partners consider immunization to be a key element of public health, a prerequisite to economic and social development and a crucial element in enabling every child to reach his/her full physical and intellectual potential. GAVI members recognized the need to:

- Reverse the decline in vaccination coverage in many countries;
- Increase R&D efforts for vaccines against disease of public health importance in the developing world;
- Revitalize global commitment for immunization at national, regional and international levels.

At the country level, governments collaborate with the Alliance partners through a national Inter-Agency Coordinating Committee (ICC), which explores ways of strengthening immunization services and the financing of those services through national, bilateral and multinational resources (WHO, 2018).

#### 2.3.3.2 The Global Fund to fight AIDS, Tuberculosis and Malaria

The Global Fund to fight AIDS, Tuberculosis and Malaria (The Global Fund) is a partnership organisation designed to accelerate the end of AIDS, tuberculosis, and malaria as epidemics. Founded in 2002, the Global Fund is a partnership between governments, civil society, the private sector and people affected by the diseases. The Global Fund raises and invests nearly US\$4 billion a year to support programmes run by local experts in countries and communities most in need (The Global Fund, 2018).

In April 2007, the board of the Global Fund to fight AIDS, Tuberculosis and Malaria agreed to consider comprehensive country health programmes for financing. The new International Health Partnership Plus, launched in September 2007, will help low-income countries to develop such programmes. The combination could lead the Global Fund to fight AIDS, Tuberculosis and Malaria to a much broader financing scope (Ooms, Baker, Zeitz, & Schrecker, 2008).

The Global Fund is a financing mechanism rather than an implementing agency. Given this nature, the Global Fund has recently been the centre of multiple debates about its funding. Vertical financing, which aims for disease-specific results, and *horizontal* financing, which aims for improved health systems, have been joined by 'diagonal' financing, aiming for disease-specific results through improved health systems. Julio Frenk and Jaime Sepúlveda describe the diagonal approach as a "strategy in which we use explicit intervention priorities to drive the required improvements into the health system, dealing with such generic issues as human resource development, financing, facility planning, drug supply, rational prescription, and quality assurance" (Ooms, Baker, Zeitz, & Schrecker, 2008).

#### 2.4 Overview of the literature

#### 2.4.1 Inclusive development and intersectionality

The disability inclusive development field of intervention emerged as a field for intervention and debate in the late 1990's following lobbying by disabled people's organisations (DPOs) and International Non-Governmental Organisations (INGOs) with an interest in disability matters (Grech, 2016). Largely located in the Rights Based tradition – in part later fuelled by the CRPD and explicit exclusion from the Millennium Development Goals (MDGs) – Disability and Development does not fit neatly into a single academic or practice discipline and there is a paucity of genuinely interdisciplinary literature, practice and theory (Soldatic and Grech, 2016). It can be argued that much of the 'noise' around the debates on disability inclusive development detracts from how we engage poor disabled women and men, boys and girls in determining a better life for themselves, and AT can also fall into that category – focusing on products, rather than people and the impact on their lives. All of this is compounded by poor evidence. Specifically, the lack of connectivity between development initiatives, innovation and market-based solutions is apparent.

DFID has one of the more developed approaches to issues of intersectionality. However, globally there is much less action than would be needed to fully understand the everyday lived realities of, for example, disabled women and girls, which are largely ignored in the literature, with some notable exceptions (Hans, 2006). Where studies on disability do look for gender impact or age impact, they often find it. Walker et al. (2012) studied the influence of slum improvement/reconstruction on boys and girls in Mumbai. They found that both disability and gender played a key role in how young people experience relocation and the effect on their well-being. For example, the new housing blocks created were often inaccessible, and "the presence of a disabled daughter was kept secret, and/or the girl was kept locked up alone in the apartment, in the interests of her safety, while family members were at work" (Walker et al., 2012, p. 120). It is clear, then, that intersectionality matters, but is rarely evidenced.

The reality is that many projects which are carrying out disability-inclusive development are still piecemeal, pilot, poorly-conceptualised or badly delivered in part because the medical and charity models still permeate. This reinforces unhelpful power relations, assumptions, stereotypes and methodologies; many interventions fail to break the "complex and nuanced feedback cycle between disability and poverty" (Kett & Groce 2013, p. 8). Neither an explicitly normative framework; nor transparent positionality or involvement of disabled people in the policy-making and programme-design-evaluation process, are commonplace. This leads to less good outcomes and reinforces the existing power structures which subjugate disabled people. AT can both help address this power imbalance and is a necessary factor in achieving disability inclusive development objectives.

#### 2.4.2 Identity and stigma

An impairment can be something a person experiences without negative association as a part of life – many people positively adopt disability as a key part of identity. This is a concept especially embraced by disability movements in the Global North. However, at the other extreme, an impairment can be something a person, or their family, is deeply ashamed of. How a person feels about using AT is then often a product of the society which they live in, and the way that society includes (or excludes) disabled people, as well as the way the AT is introduced to them. Older people, for example, who might not associate their difficulty in hearing or walking with 'disability' may be less inclined to use or 'demand' AT as their 'functional decline' is a well-established side effect of getting older. Older people in fact often reject AT due to the perceived stigma of being categorized as 'disabled'. On the other hand, people who identify as being disabled people are more frequently enthusiastic adopters of AT when it is available. It is therefore necessary to accept the heterogeneous nature of the population of

AT users and to look to enable greater acceptability of AT use within all groups of users. Much more research is needed to understand more deeply what drives this stigma within cultures and how it can be overcome.

Stigma associated with disability is pervasive in many areas of life. Disabled people face discrimination each time conversations or buildings are inaccessible; each time reasonable adjustments are ignored, and every time inclusive participation is not valued. This pervasive discrimination has a profound effect and can reinforce societal prejudices, which in turn helps to ensure they remain. When disabled people are not seen and do not have the AT they require to independently participate in life beyond their home, then others can perceive disabled people as incapable of doing so. This in turn ensures, at a societal level, that AT is dropped from the agenda, or allowed to slip to a level where the system is dysfunctional or not fit for purpose.

Alternatively, when designed well AT can become an integral part of a person's identity. People now frequently talk of "wearing their wheels", rather than using a wheelchair for example (Holloway & Dawes, 2016). Therefore, how the AT looks, its desirability, is essential to whether it will be accepted by the user. It should be of no surprise that prosthetic limbs for example which are of the wrong colour skin, will frequently be rejected by users. This would seem obvious, but the practice of donating white limbs to countries where the population is majority non-white is still in effect.

These issues of stigma, discrimination and culture require much more evidence and comprehensive systematic studies should be built in to any policy or programme to understand stigma and the subsequent barriers to disabled people. Ultimately stigma will affect the demand for AT within a Country significantly.

#### 2.4.3 The evidence base for AT: how do we know what works?

AT resources remain scarce, even though it is universally accepted as something that can significantly change the lives of disabled people by enhancing the functioning of the user. With an ageing global population, the role of AT in enhancing lives has been put under increased scrutiny. The WHO reports on Active Ageing (WHO, 2002) and Ageing and Health (WHO, 2015) highlight the challenges of functional decline which go hand-in-hand with growing older. AT has been shown to improve function and slow the decline of functions of older people, leading to fewer falls, increased independence and ultimately reduced healthcare costs (Garçon, et al., 2016). However, although evidence for all these benefits and more exist, the evidence for AT is variable and often means a systematic review of the literature is not feasible leading to researchers conducting scoping studies<sup>2</sup> (Matter et al. 2017; McSweeney and Gowran 2017) and rapid reviews (Garçon et al. 2016) of the evidence for AT.

These reviews of what is being done globally, and particularly in resource-limited environments<sup>3</sup> (RLEs), paint a bleak and uneven picture of AT research. The most comprehensive scoping review (Matter et al. 2017) within RLEs found mobility (prosthetics and wheelchairs) and vision (eyeglasses and contact lenses) dominate the published literature; together, they account for 80% of studies. In contrast, hearing (10.7%), communication (3.6%) and cognition (0.8%) are largely ignored by the research community. There is a focus on research within India and China and a paucity of research in the Middle East and North Africa (Matter et al. 2017). Two thirds of studies were observational in nature and the sample size varied widely from single case studies to trials involving tens of thousands.

<sup>&</sup>lt;sup>2</sup>A scoping review examines the extent, range and nature of existing evidence and often visualises the trends of the results e.g. a year-based trend. It does not comment on the quality of the research reviewed. In this way it is a forerunner to a systematic review.

<sup>&</sup>lt;sup>3</sup> Although RLEs occur more frequently in LMICs, an RLE may occur in a high-income country. It is simply a geographical area which has limited financial, human and infrastructural resources to provide rehabilitation.

The sample size was related to the type of AT, with contact lenses in the tens of thousands, spectacles in the thousands and mobility devices averaging around 30 people. Perhaps most troubling of all is that there were only 252 articles worthy of review by the researchers, averaging 19 publications a year over a 13-year period.

One of the few systematic reviews to be conducted specifically investigated six countries which are primed to see a rapid increase in the over 65 population within their borders, namely Brazil, Cambodia, Egypt, India, Turkey and Zimbabwe, all of which are LMICs (Marasinghe, Moreno, & Ross, 2015). Of the 538 papers found for review, only 17 papers hit the inclusion criteria (focused on AT as their primary research, had a focus on one of the six focal countries and had included people over the age of 60). Based on the evidence, the authors recommend cost-reduction as a strategy of increasing availability of AT, citing local production (e.g. Brazil), mass-production (e.g. India) and reduction of import duties (e.g. Brazil and Turkey) as possible methods for cost reduction. In addition to initiatives which drive down cost, the authors recommend: awareness raising and capacity building on AT; bridging the gap between AT policy and practice; and fostering targeted research on AT.

#### 2.5 Products

#### 2.5.1 Mobility

Most of the research carried out to identify barriers to AT for mobility access in LMICs has been focused on wheelchairs and prosthetic devices (Jefferds *et al* 2010, Marino *et al* 2015). Findings from different studies highlight how, despite the improvements witnessed in the last decade, access to appropriate mobility aids in many LMICs is still a challenge (McSweeney & Gowran, 2017).

The high cost of most AT for mobility represents a significant barrier not only for the millions of disabled people who are often poor and unemployed (and therefore cannot purchase privately), but also for a system of public provision that largely relies on international donations (Marino *et al* 2015). Moreover, mobility products manufactured in high-income countries are also designed for users in high income countries and are often inappropriate for the physical and social context of the low-middle income countries in which they are imported and distributed (Jefferds *et al* 2010).

Many of the barriers to the access of AT for mobility are related to the characteristics of the service provision system rather than the characteristics of the products themselves (McSweeney & Gowran, 2017). The provision of devices such as wheelchair and prosthetics needs to be part of a more comprehensive rehabilitation process. Unfortunately, in RLEs rehabilitation and assistive device provision centres are rare and far apart. Therefore, many users living in rural areas don't have access to nearby rehabilitation or AT centres, and might need to travel for days to get their prosthetic limb fitted or receive a wheelchair skills training session (McSweeney & Gowran, 2017, Marino *et al* 2015). The fragmented nature of the service provision system would already represent an important barrier if the provision of AT for mobility could be carried out in a single session. However, the need for prolonged interaction between users and the AT workforce, combined with the need for repeat visits to clinics, considerably widens the access gap.

#### 2.5.2 Vision

Available research concerning the provision of AT for vision in RLEs is mainly focused on spectacles (Holden *et al* 2000, Wan *et al* 2015, Ayanniyi *et al* 2010). Other AT, such as braille slates and styluses, magnifiers and screen readers are only considered in relation to access to ICTs and for the purpose of inclusive education (Pal *et al* 2011).

AT such as magnifiers, white canes and reading glasses are considerably cheaper than mobility products such as wheelchairs or prosthetic limbs (Pal *et al* 2011). However, even the limited cost of a

pair of reading glasses is often too great for many disabled people and the fear of damaging such an expensive piece of equipment can lead a person to wear their glasses less often for fear of damaging them (Ayanniyi et *al* 2010). Furthermore, many spectacles provided in less resourced settings are of poor quality, featuring poor quality lenses and unattractive frames that might reinforce stigma (Holden *et al* 2000).

In keeping with the evidence from the mobility sector, the provision of spectacles in LMICs relies heavily on a donor-based system and the practice of providing recycled spectacles in RLEs is still common across many organisations (Holden *et al* 2000, Wan *et al* 2015). In addition to the ethical consideration that this delivery system raises ("is it appropriate to distribute in low resourced settings spectacles that are considered unfit to be used in more resourced areas?"), recent studies show that the provision of recycled glasses is neither more cost-effective than the local production of customized glasses nor is sustainable in the long term (Wan et *al* 2015).

As was seen for mobility, one of the main barriers to access of AT for vision in RLEs is related to the insufficient reach of the existing provision system. Many people living in rural areas don't have access to centres where vision products can be effectively provided, and the lack of a suitably trained workforce makes it difficult for existing services to scale up and improve their reach (Holden *et al* 2000, Pal *et al* 2011).

#### 2.5.3 Hearing

In recent years the analysis of the barriers and facilitators related to the provision of hearing aids and other AT for hearing impairments in RLEs has begun to attract significantly more attention within the research community (Tesni & Santana-Hernandez 2014, Carkeet *et al* 2014, McPherson 2014).

Like for all the AT previously discussed affordability is still one of the major factors that limits access to hearing aids (McPherson, 2014). For example, in a study carried out in the Dominican Republic, the average cost for a hearing aid that was considered fairly priced was between 180 and 190 USD, which roughly corresponds to one-month's rent for a small house (Carkeet *et al* 2014). Furthermore, high equipment cost is an important barrier for many hearing aid provision centres as the equipment required for their calibration is expensive and calibrating hearing aids is an essential step to ensure the provision of well-functioning products (Carkeet *et al* 2014).

Hearing aids provision is also severely hindered by the lack of properly trained personnel. Audiologists are highly skilled professionals, rare in many RLEs, and audiological screening and provision of hearing aids from community health workers and special needs teachers are still uncommon occurrences (McPherson, 2014).

Finally, the provision of hearing aids and other APs for hearing impairment should only represent a step in the more comprehensive interventions targeting people who are deaf or hard of hearing. Interventions for community awareness, inclusive education and employment are also necessary to deliver a real impact on people lives (Tesni & Santana-Hernandez, 2014).

#### 2.5.4 Cognition

It is widely acknowledged that the number of people with cognitive impairment worldwide has witnessed an exponential growth over the last two decades, and the current trend is expected to increase particularly in LMICs as the population, on average, lives longer (Wimo *et al*, 2013). Yet, research concerning development, provision and access to cognitive AT in RLEs is virtually non-existent (Borg *et al* 2011, Matter *et al*, 2017).

The study by Assis *et al* (2009) shows that simple cognitive aids such as calendars, activity boards and manual routine organizers can be developed at relatively low cost and can yield considerable benefits for individuals with cognitive impairment. Furthermore, AT for cognition can provide the necessary support to attend school for many children with learning disabilities (Adebisi *et al*, 2015). However, in many LMICs, the lack of awareness concerning AT which can aid cognition, combined with a lack of policies supporting the provision of cognitive aids, the unavailability of training opportunities for a specialized AT cognition workforce and the stigma surrounding people who have cognitive impairments represent a wall of barriers to the access of appropriate AT for cognition (Adebisi *et al*, 2015).

#### 2.5.5 Communication

Even though communication impairments are one of the most frequent impairments associated with disability in many LMICs, research focusing on the provision of augmentative and alternative communication (AAC) devices in RLEs is currently scarce (Eide & Øderud, 2009).

As was previously mentioned for cognition, one of the more significant barriers to the provision of appropriate AAC technology in RLEs is related to the lack of awareness surrounding this kind of AT (Wormnæs & Abdel Malek, 2004). Many speech therapists do not feel that they have the appropriate competency to advise clients who might benefit from AAC. Furthermore, the lack of awareness of many parents and caregivers – who can be able to overrule the user themselves – can prevent AACs from being used, as they are mistakenly thought to prevent the user from expressing themselves verbally and seen to potentially increase the stigma surrounding the user (Wormnæs & Abdel Malek, 2004). To further complicate matters, many AAC devices are perceived as complicated, unreliable and unsuitable for the local context (Baxter *et al* 2012). Communication is often shaped by the social context of the user and it is unlikely that AAC devices developed and produced in high income countries will comply with the social context of LMICs (Geiger 2010).

Finally, the lack of integration of AAC devices into educational end employment systems represent an important barrier which is unlikely to be overcome by technological development alone and will require a holistic approach encompassing policy, legislation and infrastructure building (Samant *et al* 2013)

#### 2.5.6 The evolving concept of Assistive Products

Assistive Products (APs) are defined by the WHO GATE community as "any product (including devices, equipment, instruments, and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote their wellbeing" (Khasnabis, Mirza, & MacLachlan, 2015). This is to be understood as within the definition of AT, which also includes the services around the APs needed to enable the individual to use them to improve their well-being. However, even within this definition there is a shift within the marketplace when it comes to APs.

New and emerging APs, like mobile apps, can undertake the functions of traditional APs in some cases and, within the definition of the WHO, these then fall under healthcare technologies. There are a growing number of products on the market that blur the boundary of what is and what isn't an AP. The iPhone is a classic example; although not accessible (due to cost) to many disabled people in LMICs, within higher income settings it has become a go-to technology for all people and has accessibility features baked into the design, which means it is usable by a much larger number of people. This removes a vital component of use of APs stigma (Shinoara & Wobbrock, 2011). One of the reasons for the popularity of the iPhone is not just due to its revolutionary functionality, but that people identify with being an owner of an iPhone, and like the fact that they can own and operate one. In contrast, APs often add to the stigma associated with being a disabled person.

However, there is a dichotomy when it comes to app and software developers. Many developers prefer to work in what they consider the 'accessibility' space, as, once something is developed within the healthcare technology space, level of bureaucracy to get a product to market is considerable. Seeing AI and Soundscape, both advances from Microsoft, started as accessibility applications but ended up firmly in the healthcare space. This had consequences for product development timelines, but also now positions Microsoft and others as emerging contributors to the AT space.

#### 2.5.7 Digital and emerging products

The world is more digitally connected and this in turn can ensure disabled people are less excluded, as well as providing a hotbed for new products (as seen previously).

Increasingly, digital technologies are levelling the playing field for disabled people by providing the service of an AT (Raja, 2016). Mobile phones can convert text to speech for visually impaired people, for example. The Internet is also opening education and life-long learning opportunities for disabled people (Broadband Commission for Digital Development, 2013).

More generally, the increasing coverage of smart phone use is providing new avenues for activism and collectivism as well as communication. The internet and ICT are disruptive technologies, capable of facilitating the social, economic and civic participation of persons with disabilities. However, there is a significant need to build stakeholder capacity for their potential to be fully realised (Raja, 2016).

#### 2.5.8 Usability and abandonment of AT

When AT matches the needs of the user and is well integrated into their life, it can have a hugely positive impact. However, when the AT doesn't respond to the needs of the user it's likely to be abandoned. The abandonment of AT is a pressing issue with an estimated rate ranging from 8% to 75%, depending on the technology (Scherer, 1996). Hearing aids can be abandoned by up to 75% of users (Scherer, Sax, Vanbiervliet, Cushman, & Scherer, 2005), whereas wheelchairs average 50% for the spinal injured population in the UK (Rose & Ferguson-Pell, 2002). Generally, an abandonment rate of 30% is accepted as being a true reflection of how many times people simply stop using an AT (Holloway & Dawes, 2016). Abandonment is a core part of the systems failure which exists around the generation of a fully functioning market for AT.

One of the main predictors of AT abandonment is the lack of user involvement during the selection process (Kittel et al., 2002; Phillips & Zhao, 1993; Riemer-Reiss & Wacker, 2000). This lack of consultation with the user leads to the scarce consideration of users' needs that in turn leads to a poorly matched AT. In contrast, when AT is provided in a collaborative environment that includes training and appropriate matching to needs and environmental context revolutionary results can be seen. However, often one of these links breaks down and the AT is then not fit for purpose, and products are simply abandoned by users (Phillips & Zhao, 1993).

The abandonment of AT has several negative consequences. In practical terms, the abandonment of AT results in the loss of opportunities for the person and the waste of public and/or private money used for its purchase (Phillips & Zhao, 1993). Furthermore, the users and their families often invest significant time and effort in the selection of AT and have high expectations for the impact that the AT will have on their lives (Kintsch & DePaula, 2002). When an AT is abandoned, many disabled people end up blaming themselves for the failure of the AT (Hocking, 1999). This can lead to a feeling of helplessness and frustration, lowering the expectations towards the potential benefits of AT in general (Bühler & Knops, 1999; King, 1999).

The use of User Centred Design (UCD) and Participatory Design (PD) methods in the development of new AT that better match the needs of users has the potential to reduce the abandonment of AT (Wilkinson & De Angeli, 2014). These design approaches can be used to extend the reach of commercially available AT and to help develop bespoke AT when mainstream solutions fail. Mainstream AT is often unable to satisfy the needs of many users, particularly when the characteristics of the user, or the situation in which the AT should be used, fall outside the 'normal' range (Barbareschi & Holloway, 2018). The direct engagement of disabled people in AT design enables the development of new bespoke AT that fills the gaps left by commercially available mainstream AT (Barbareschi, 2018). Finally, the PD of new AT offers an opportunity for empowerment, increasing confidence and independence for disabled people not just through the outcomes of the AT design, but also through the inclusion of users in the process (Hurst & Kane, 2013).

#### 2.5.9 Disincentives to innovation in AT

There is no lack of innovation in the field of AT. We have recently had the first 3D printed wheelchair, a feat of engineering which is quite extraordinary, creating a supremely lightweight but also customfit design. 3D printing is also beginning to be used to enable humanitarian organisations to print orthotics and prosthetics in crisis situations (e.g. <u>HI</u>), and by wheelchair providers in LMICs to provide specialist seating solutions which were otherwise unaffordable (e.g. <u>Motivation</u>). All these innovations have been made possible by the advent of digital fabrication which would have been unimaginable a decade ago. The problem is not with pilot programmes or the ingenuity of finding solutions; it is bringing these solutions to scale. For this, innovation is needed not just in products, but in financing models, in systems, and in how disparate sectors of the AT community work together to provide and scale service provision.

The incentives for the larger companies operating in this space do not encourage innovation or scalability of more affordable products. Blatchford's and Motivation are two AT providers who have managed to grow an international reputation whilst keeping a UK base<sup>4</sup>. Blatchford's continue to push the boundaries of what is possible for lower-limb amputees, recently winning the prestigious MacRobert Award, run by the Royal Academy of Engineering, for their new Link Limb system (RAE, 2018). However, such innovations are not available through well-established health care systems such as the NHS, let alone LMICs, due to the cost. Motivation on the other hand are globally recognised as leaders in the field of AT, specifically around their technical knowledge of wheelchair design and provision. Last year alone Motivation reached 80,000 people in over 60 countries (Motivation 2018) which shows some progress, but there is still a huge amount to do to take this kind of model to scale.

The people who are innovating in this space are those on the ground, capable of identifying the problems and creating solutions that will work in the local environment. Funding for such work comes from a number of sources: through research grants via 'donors' (e.g. DFID, USAID), through competitions (e.g. Google Impact Challenge, Toyota Mobility Foundation's Mobility Challenge), or through core funds with a charity which have come from donations. Until recently, within the UK at least, funding linked to LMICs and the traditional aid budget was separate from the UK research council funding. This changed in 2015 with the announcement of the Global Challenge Research Fund (GCRF). GCRF is a £1.5 billion UK Government initiative to support cutting-edge research that addresses the challenges faced by developing countries (UKRI, 2018). Currently the most targeted AT research from this fund has come via the Engineering and Physical Sciences Research Council (EPSRC),

<sup>&</sup>lt;sup>4</sup> <u>https://www.raeng.org.uk/news/news-releases/2016/june/world's-most-intelligent-prosthetic-limb-wins-uk's</u>

with £4.8 million of funding spent on 8 projects<sup>5</sup> which address the needs for affordable prosthetics and orthotics in developing countries. To put this investment in context, the current EPSRC budget in 'Assistive Technology, Rehabilitation and Musculoskeletal Biomechanics' is £75 million as of June 2018. This means 93% of funding is spent on improving AT and better understanding of the biomechanics to use AT for the 10% of people who already have access.

Once innovations for LMICs are proven, it is not a simple road to getting them scaled. The funding within Innovate UK for example, a recommended route for transferring technology from universities and proof-of-concept to the market place, sets a number of success criteria on the impact on the UK economy, but what if the primary aim is not to create jobs in the UK, but instead to help disabled people live better lives in LMICs; how then is this funded? To overcome restrictions in funding for innovation, charities such as Motivation have begun creating their own challenge funds to allow them access to funds which will ensure they can bring innovative ideas to market (Motivation, 2018).

#### 2.6 AT provision within humanitarian crises

There are more displaced people on our planet than at any time since the Second World War (Betts & Collier, 2018). Most of the 65 million people displaced from their homes remain within the borders of their home country; a third leave and at that point become refugees. The traditional drivers of forced migration – war, human rights violations, persecution are now joined by climate change, which is driving higher numbers of people to have to leave their homes (Betts & Collier, 2018). This has resulted in 9.3 million disabled people being forcibly displaced around the globe. The International Disability Alliance (IDA) have recently communicated their deep concern for the way in which disabled people are being treated during humanitarian crises at the Conference of State Parties and are calling for action which looks to ensure the immediate and ongoing response is fully inclusive of the needs of disabled people.

Disabled women, in particular, often continue to suffer long after the initial disaster is over. A recent review of disaster risk reduction (Twigg, 2015) highlights the case of paraplegic women in Pakistan following a recent earthquake, who were largely abandoned by their husbands and received significantly reduced care from their families. Their husbands married a second wife or intended to do so. In contrast, paraplegic men remained cared for by their wives and families. Further exclusion of women included girls being taken out of school to take over housekeeping chores due to their mothers having become disabled (Irshad, Mumtaz, & Levay, 2012).

Disasters and conflict zones not only increase the number of disabled people – both by causing bodily harm but also by creating an inaccessible and hostile environment – they also marginalise disabled people. Disabled people are often excluded from the early stages of a humanitarian response (UN General Assembly, 2016). Creating accessible environments and ensuring AT reaches people in disasters is challenging. However, innovation is occurring, and we highlight two examples of the way in which both the environment and the AT is advancing:

- AT: New technologies, specifically new manufacturing methods are beginning to change the way AT can be delivered in conflict zones. 3D printing has shown promise as a way of rapidly responding to bespoke user needs, for example a recent trial by MSF (Doctors without Borders, 2018). However, there is little published literature, or evidence on the benefits and possibly disadvantages of using these newer approaches, especially at scale.
- 2. Accessible Environments: The accessible latrine slab is now being designed by UNICEF though an open tender for competitive designs (UNICEF, 2018). As part of the competition they

<sup>&</sup>lt;sup>5</sup> A full list of the projects funded can be found here:

http://gow.epsrc.ac.uk/NGBOViewPanelROL.aspx?PanelId=1-4KT840&RankingListId=1-4KT85P
highlighted the need to: consider universal designs to accommodate more users; designing with the users; and gathering feedback from the field. In addition, they looked to allow for more innovation through supplier proposals by allowing flexibility in the invitations to bid.

AT plays a key role in the context of humanitarian crises. A global consultation carried out by Humanity & Inclusion (HI) in 2015 found that disabled people too often fall through the cracks of humanitarian response. Three quarters of the respondents reported that they did not have adequate access to basic assistance, such as water, shelter, food or health. In addition, the specific services that disabled persons might need, among which are assistive devices, were not available, further impeding their access to mainstream assistance (HI, 2015). These facts make it extremely important that humanitarian action is disability inclusive and that measures are taken to ensure that disabled persons are not left behind in humanitarian contexts.

#### 2.7 A systems approach to AT provision and market failure

Despite clear personal need, there is a market failure in the delivery of AT. This was the starting point for the establishment of the WHO's GATE initiative. Its focus has been on developing a Priority Assistive Products List as well as developing test programmes in country, producing training for communities in use and repair of AT, and tackling market failures. GATE estimates 90% profit margins are made by a monopoly of companies who have little incentive to innovate or compete.

The market is failing as there is limited demand for AT globally. This lack of demand is in part due to the lack of evidence of the effectiveness of assistive products, and partly due to the way in which AT is provided. AT is frequently provided in LRS by donations via charities (McSweeney & Gowran, 2017; Visagie, S. et al, 2018; Marino, M *et al*, 2015; WHO, 2016). These products are of variable quality, and some do not provide the essential service elements of AT and instead simply provide the product independently; a problem which is particularly problematic for wheelchair (McSweeney & Gowran, 2017) and prosthetic provision (Visagie, S. *et al*, 2018). The provision of AT from outside a service results in the product being of little or no use to the person and can even cause physical harm to the user (WHO, 2017; Rohwerder, 2018).

The effects of such provision practices go well beyond those on the individual who has received the, in effect, unusable product. As identified in Visagie, S. *et al* (2018), these practices also impact on the market in such a way as to reduce the responsibility of government to ensure national level access to AT. Furthermore, by providing products which are unusable, the societal norms of disabled people being in effect invisible within society are reinforced; and when disabled people are not seen to be full members of society it is easier to continue to exclusionary practices.

To create a system which works within a Nation State it is important to take a systems approach. For AT provision this starts with mapping the Assistive Technology System Gap (MacLachlan, 2018), which is a cascading number of factors, which tend to lead onto one another. The list starts with a recognition of the need for APs for people, this leads to the need for availability, affordability, accessibility, adaptability, acceptability, quality and most importantly use (MacLachlan & Scherer, 2018). The system within which these cascading factors works involves the GATE's 5Ps of Provision, People (users), Products, Personnel (AT professions and those assisting AT use) and Policy, along with Place and Pace. The first and most important step is to ensure the policy framework recognises the need for APs, this must be conducted through structured assessment which assesses what exists (Amin, 2011) and what is needed (Huss & MacLachlan, 2016).

However, once this first, important, step is achieved it can still be difficult and even impossible for governments to ensure AT provision, due in no small part to the cost of the products, training of service personnel and delivery of services. To reduce the cost of products, researchers suggest governments remove barriers to market entry to allow markets to develop and eventually thrive (Smith et al 2016). This is important, but the problem is somewhat larger than a Nation State's tariffs. It is here that the concept of market shaping enters, where nations can come together to pool their purchasing power. The role of agencies such as DFID in enabling this is critical (MacLachlan, 2018). Failure to affect change within the provision of AT at a systems level may push AT to become increasingly siloed, divisive, and inequitable, effectively undermining basic principles of social justice, on which the CRPD, as well as other human rights Conventions, are based (MacLachlan, et al., 2018).

#### 2.8 Results: Barriers to accessing Assistive Technology

The literature presented clearly shows the complex map of factors which effect the provision of AT globally. These are summarised in Figure 7. Overall it is clear that different levels of barriers are conspiring to make the provision of AT a 'wicked problem'. The problems within and across the 5Ps are now discussed.



Figure 7: Barrier map under the 5Ps

#### 2.8.1 People

People are discriminated against and there is a general lack of awareness of the fundamental, positive impact AT can have on an individual's life. This is not helped by a lack of impact measurement and an environment which can make the use of AT impossible. There is an increasing understanding of the need for barriers to be removed from both physical and digital spaces, and to ensure equal access to the internet as well as cities for disabled people.

- Awareness lack of awareness of user needs, the benefits to individuals and society of meeting them, the consequences of not meeting them and state obligations to address people's rights through UNCRPD, the WHO resolution and the SDGs.
- **Research/impact measurement** a lack of a robust research and evidence base, which prevents the ability to scale pilot projects.

- **Place** the potential '6<sup>th</sup> P' sits under People and directly relates to the physical environment and conditions in which people live. The concept of Place also extends to the digital space in which people increasingly operate.
- Stigma Disabled people are continually discriminated against, and this is a barrier which prevents disabled people from engaging in society, as well as preventing people from being visible to society.

#### 2.8.2 Products

- Standards Globally accepted product specifications and standards do not exist for all
  products on the APL, so purchasers are having to assess products of varying quality as well as
  cost when deciding what to procure. Without standards it is often the case that the person
  making purchasing descriptions will be unaware of the nuances of this trade-off, and opt for
  more of the cheaper product, not understanding the potential harm delivery of a sub-standard
  product can do. This decision making in turn can add additional cost to the users and the
  providers of healthcare, as secondary complications may arise from use of a product which
  has been poorly designed.
- **R&D** product R&D is characterised by limited investment, innovation and R&D in supply due to limited buying demand, and lack of publicly funded research investment. The poor design of some products and the lack of R&D into AT which is fit for purpose in resource-poor settings results in high abandonment rates of AT. This problem is exacerbated by a lack of user involvement in the design process.
- **Design** inappropriate design relates to both design process and outcome. Inclusive design places the end user at the heart of the process, creating more appropriate outcomes. AT is frequently designed to be unaffordable and unsuited to the environments found in LMICs. Furthermore, repairability within the local context is very rarely considered.
- **Demand** volume of demand is too low to encourage the development of supply. This relates to tariffs and bulk buying potential. Demand is depressed by high prices. Also, demand is fragmented across multiple small buyers. Manufacturers don't have visibility of demand. One of the critical issues is that the buyer is often not the user. Ultimately, there is often little demand for AT both by the user (due to a lack of information and understanding of the benefits of AT) and by the purchasers at national levels, as AT competes for healthcare budgets which are often thinly stretched.

#### 2.8.3 Provision

- **Investment** low levels of finance and investment in supply, distribution and delivery systems mean overall infrastructure is not present to accommodate scale up of AT provision.
- **Distribution systems** distribution systems (moving products from point of manufacture to point of delivery) are inconsistent in terms of shipping, stock, lead times, packaging and logistics. Often services are left without products.
- Service network (urban and rural) to scale up the provision of AT nationally, a network of AT services needs to be set up. Services include screening, diagnosis, fitting, and ongoing service/replacement. At present many services are centre based in urban areas, but to reach those most in need more grassroots service structures need to be established. Also, there is a missed opportunity to integrate with existing services e.g. health or education.
- **Technology** emerging and evolving technologies are changing the way AT products are delivered i.e. self-manufacture, bespoke services, remote access. However, currently new technology and advances overly focus on high-resource settings.
- Cost cost is a critical problem for provision, and one which is seen as an ultimate barrier.

#### 2.8.4 Personnel

- Service models many AT service models are dependent on the availability of highly qualified professional staff and can be very labour (and therefore time) intensive. Alternative models that help scale up AT provision, including use of technology, need to be developed and trialled. Globally accepted standards for service models could also be created.
- **Trained staff** there is a general requirement that personnel involved in AT assessment and prescription are highly qualified. There are not enough staff at grass roots level that can show competence to deliver AT effectively. There is frequently resistance to new systems of training, including approaches to task-shifting, which further reinforce this barrier.
- **Cost** Frequently the service element of AT costs far more than the unit cost of products, and the reduction in overall cost must be addressed whilst ensuring quality of product and service.

#### 2.8.5 Policy

The lack of a clear policy for the provision of AT remains a barrier in some countries and regions. However, the larger barrier is in the implementation of these policies, which often necessitates collaboration across government ministries, and therefore can get stuck in bureaucracy without a clear defining mission for people to get behind.

One of the largest barriers for governments to deliver their policies or visions for policies is understanding the infrastructural framework for provision of AT i.e. finance and resources. Procurement at scale remains a barrier linked to this lack of infrastructure, as does supply. Without a solution to how a country will both procure at scale and be able to supply the products across the country, the AT problem can often feel overwhelming.

- Legislation many governments have ratified the UNCRPD, but few are meeting their obligations, in part due to a lack of implementation. National legislation should be encouraged to embed meeting these obligations in day to day operations and budgets.
- Governance often where government funding is available for the provision of AT it is not effectively managed, and systems are not clear and transparent for all involved. Additionally, there is a lack of regulations applied to procurements (to ensure quality). The other regulatory issue is related to permitted service providers – sometimes regulations serve as a bottleneck to expanding services.
- Procurement procurement planning is often driven by budgetary requirements rather than
  user needs. The reverse is also true: there is no budgeting for procurement in advance. There
  remains a lack of consolidated distributors that can help rationalise procurements and ensure
  quality. If user needs are established in both quantity and quality based on WHO
  specifications, then overall budgetary requirements could be established. Once need is
  established, governments can allocate resources for procurement. If sufficient funding is not
  nationally available, alternative and transitional financing systems could be explored to
  supplement government funding.
- Supply many governments lack policy interventions that encourage the supply of AT products e.g. restrictive import and export policies, customs and duties, sales taxes, transportation limitations and cross border trade routes. Often there is emphasis on national/local production to help develop the economy, to the detriment of quality products that meet user needs. Alternative supply and distribution systems can be explored to address these issues. Greater impact measurement will also show the societal impact of appropriate AT provision and its long term economic benefits.

#### SCOPING RESEARCH REPORT ON ASSISTIVE TECHNOLOGY



Figure 8: WHO/Eduardo Martino

"There is a need to work with key stakeholders to change the way they think about this market opportunity, in the same way the landscape changed for HIV drugs."

> AT interviewee's response during the initial stakeholder interviews

## **3** Primary scoping research

The initial objective of the primary scoping research was to gain a deeper understanding of the barriers affecting the provision of AT globally, with particular interest in DFID priority countries. This initial research was undertaken to understand what should be prioritised in terms of global investment opportunities, to ensure greater provision of those in need of AT. The GDI research team carried out primary research through a combination of primary interviews, workshops and events over six weeks in early 2018.

#### 3.1 Methodology

#### 3.1.1 Stakeholder engagement

The first stage of the scoping research involved identifying stakeholders who might have an interest in, or would be impacted or affected by, a proposed AT intervention. The stakeholder group can include the whole range from impacted individuals, DPOs, communities and groups, to knowledgeable experts, implementers and those who will be held ultimately responsible, such as chief executives or ministers, among others. Stakeholders, as defined in theory, are groups or individuals who can affect or are affected by an issue. Stakeholders are an important source of information in research, providing critical perspectives and new insights on the complex determinants of AT and its markets. The intersection of built and social environments with disability, innovation, and assistive technologies is an area of research that is fundamentally interdisciplinary and would benefit from a better understanding of stakeholder perspectives (Schiller, Winters, Hanson, & Ashe, 2013).

#### 3.1.2 Dataset

Field notes collected from researchers taking part in the different scoping exercises were gathered together and organised according to their sources. In total, notes from 43 sources were analysed. 23 came from semi-structured interviews that were carried out with experts in the fields of AT, particularly in relation to the implementation of projects that improve the access of AT in developing countries. We recruited interviewees with substantially different backgrounds, who had expertise in different types of AT from prosthetics and wheelchairs to hearing aids and communication boards. Interviewees worked in different developing countries and were employed in various sectors including academia, industry and NGOs (see the specific section for more details). 18 of the dataset's sources come from field notes collected during meetings with stakeholders such as funding agencies, research partners and AT providers. Finally, two sources were generated from the comprehensive reports written after the East African Deep-Dive scoping exercise carried out in Kenya and Uganda.

#### 3.1.3 Method of data analysis

Due to its rigour, flexibility and appropriateness in summarizing relevant features of complex datasets including different sources, thematic analysis was chosen as the analysis method for this scoping research (Braun & Clarke, 2016). Field notes were analysed and coded using a hybrid deductive and inductive approach as outlined by Fereday & Muir-Cochrane (2006). Five broad areas to categorise barriers, facilitators and opportunities for improving AT access in developing countries were identified and prioritised according to the 5Ps model formulated by GATE: People, Products, Policies, Provision, Personnel (WHO, 2017). Data sources were initially revised individually and significant parts relevant to these five areas were highlighted and annotated to create content labels and descriptive codes. A first inductive analysis was conducted to identify sub-themes for each area. As the analysis progressed, codes were compared, renamed, split and combined to create the most comprehensive and coherent description of the data. Similarly, codes assigned to each area were grouped into relevant sub-themes in an iterative fashion where sub-themes were first defined as they emerged and subsequently reviewed, refined and renamed in an iterative fashion to ensure the correct interpretation of the data (Braun & Clarke, 2016). A third inductive analysis was conducted to identify other relevant codes, emerging from the data collected, that had not been previously assigned to the five areas. After comparative examination and triangulation with pre-identified codes and themes (Silverman, 2006), two additional themes were extracted from the data: Creating networks of disabled people for support, advocacy, and to promote awareness; and need for an accessible environment.

#### 3.2 Results

The results are, once again, discussed within and across the 5Ps framework.

#### 3.2.1 People

"I wish for a day I can go to a bus stop, take the bus, get out to do some shopping in my venue and go back, but [currently] nothing is accessible"

Female wheelchair user, Kenya

#### 3.2.1.1 Need to measure impact

There was acknowledgement of the work done by the WHO and others in quantifying the number of disabled people globally and in quantifying the gap in the need for AT. This work to highlight the poor availability of devices compared to the ever-growing need of the worldwide population, was seen as an essential first step in enabling progress. However, there was a recurring theme for a need for better

evidence on the impact of AT to inform decision making. The positive impact of AT can hardly be summarised "with a dichotomous score", where the person has either access to the AT or not. Access to appropriate AT often translates into better education opportunities, increased chances of employment and financial independence, to name a few. There is a need "to capture the huge benefit of [going from] being housebound to working rather than just less blurry [lines]" (research interviewee). It was seen as essential that evidence on the impact of AT cuts across multiple domains of well-being. One such example to try and assess the impact of going from one extreme (housebound) to another (working) being trialled assesses three domains: "poverty, quality of life [QoL] and mental health", using a face-to-face questionnaire. There was acknowledgment that these various impact measurement approaches could and should be developed into a unified toolkit which would have a series of "indicators which could be collected over e-platforms". As highlighted by stakeholders, this is important at several levels as it could not only be used to build business cases to motivate investors, but also to prioritise interventions according to their benefits rather than based on the low cost of implementation.

There was also acknowledgment for the need of building on the data which is already there but is often siloed in individual clinics. In many sectors, for example prosthetics, there are large databases of users and provision of AT, however QoL measurements are not routinely gathered, and this data is not shared: "[We] currently have a patient database of (11,000) people; it must be similar in UK clinics" – but there is no knowledge of how to better integrate or share the knowledge from these databases.

Stakeholders believed it would be interesting to explore how to more accurately capture the changes in people's QoL dynamically, perhaps using smartphones or activity monitors. However, it was acknowledged that this would require additional research to ensure privacy and acceptability issues were fully considered. This would necessitate a co-development process which would need a full range of stakeholders. A second point raised by the large number of individual databases was how to share data across countries to build a larger and more comprehensive dataset, to aid decision making and sharing of best practice.

#### 3.2.1.2 Stigma and discrimination

Despite the progress that had been made in many countries in recent years, many stakeholders felt that "very strong" stigma towards disability is still experienced. Discrimination towards disabled people was seen as different depending on a person's type of disability. Groups that were mentioned frequently as being most discriminated against were the deaf-blind community and people with intellectual disabilities. Although discrimination and stigma are worse for some groups over others, it was clear that it pervades all sectors of the disability community. For example, Jacob<sup>6</sup>, a wheelchair user from Kenya, explained his experience of applications being unassessed when he applied to do a course to become a counsellor. After several trips and eventually refusing to leave a building before speaking with the director of the centre, he was given an explanation: "the course takes place in rooms upstairs and therefore you cannot attend". Perseverance and having the law on his side allowed Jacob to overcome such blatant discrimination and eventually half of the library was moved upstairs, making room for counselling classes to take place on the ground floor. There was also consideration for overcoming stigma through self-employment. One prosthetic user from Uganda states: "[I] would prefer to be self-employed as there is a lot of stigma from employers and … it is harder to re-train careers once you get older."

<sup>&</sup>lt;sup>6</sup> Name changed for the purposes of this report, all other details are accurate

The impacts of stigma were well voiced by all the stakeholders, who highlighted that it leads to social exclusion and has an "incredibly negative impact on the life of the person". Interestingly, rural communities were described by stakeholders as being potentially both the most supportive and the most stigmatising. Generally, it was felt that increased awareness and increased social participation in everyday life will be the most effective ways to reduce stigma around disability. Additionally, other stakeholders highlighted the important role that DPOs can play in increasing social awareness at both general and government level. Unfortunately, some disabled groups lack representation, and this means that they are more likely to be stigmatised in their everyday context and are also more likely to be overlooked by government initiatives. In other cases, the law of a country can prohibit DPOs from advocacy work to overcome discrimination. For example, one interviewee explains the situation in Ethiopia: "The 2009 Ethiopian Charities and Societies Proclamation restricts DPOs and Federations from engaging in advocacy and lobbying – they can only engage in awareness activities. This has made the DPOs weak."

#### 3.2.1.3 User engagement and user-centred design

Direct engagement with users at every step of AT is considered extremely important by most stakeholders. Design experts made specific reference to toolkits to aid best-practice design methods such as "the Human-Centred Design Toolkit<sup>7</sup> designed by IDEO and funded (at least originally) by Bill Gates", and to the designs of Motivation wheelchairs as examples of best-practice designs. In both instances, as in global best practice of all product design, products which are designed with users are ultimately much better in meeting user needs and therefore are used more and abandoned less.

It was acknowledged that in low resourced settings user engagement is not always sought, and many countries still rely on more medically driven top-down approaches. There was also a distinction made between the needs of users in lower and middle-income countries with a need to "differentiate strategies for low and middle: low and middle income are two quite different categories: there is a term 'least developed countries. Also, these different terms will not mean the same for different countries – i.e. each situation or country will be fairly unique."

Beyond user-centred design, stakeholders felt a more proactive approach to user engagement was required, one that motivates the individual and increases chances for more active participation in everyday life after the provision of the AT. Finally, it was felt that engaging with users helps to negotiate expectations as the users can better understand the functionality and the potential of the AT.

#### 3.2.2 Products

"The aim is for assistive technology to be not only helpful and accessible but also a pleasant user experience – an aspect often overlooked."

Research interviewee

#### 3.2.2.1 Affordability, availability and quality

Affordability was mentioned by almost every interviewee. Specifically, the full cost of AT was noted, which was more than the cost of simply the design, development, manufacture and delivery of the product. Many stakeholders noted that the cost of the service is frequently more than the cost of the

<sup>&</sup>lt;sup>7</sup> http://www.designkit.org/human-centered-design

product. There is a clear link here to personnel and training, which is acknowledged and parked until section 3.2.4.

The unit cost of an AP is an issue in and of itself and is an issue which disproportionally affects different AT. Hearing aids were singled out as needing innovation within the product and manufacturing to drive down the cost, with initiatives for mobile platforms to replace some of the functions of hearing aids noted as a possible mechanism of having a cost-effective AP for hearing loss. More generally, new technology, sometimes referred to as 'leapfrog' technologies, were mentioned with both enthusiasm and caution, sometimes by the same person. For example, the use of 3D printing in the prosthetics space was encouraged by some as they insisted future investment in this space should "explore the use of new technologies (3D printing) and its applications and benefits in low resource settings (e.g. enabling more bespoke seating for those currently underserved, local production, upskilling the local work force)". Others cautioned against specific technologies believing a "healthy level of caution needed" when introducing new technology. However, those who cautioned against new technologies were also enthusiastic about their potential, but simply wanted "robust evidence" to accompany them.

It was noted by many that reducing the cost should never come at the expense of the quality of the product. Cheap and low-quality components or clunky user interfaces due to poor testing or development will inevitably result in inadequate AT that are likely to be more harmful than beneficial.

Finally, AT provided in LMICs should be targeted to the specific user group and the context of use. Appropriateness should be considered not only in relation to more obvious physical requirements (e.g. a wheelchair for use in rural Uganda should be suitable to use over rough terrain), but also in relation to cultural and social elements (e.g. communication boards should display images that consider the cultural context and religious belief of the individual). Many stakeholders felt that new technologies could significantly contribute to the development of AT that can better respond to the need of people in LMICs. However, several of them highlighted the need to keep the focus on the goal of the project rather than the technology employed to achieve the goal.

#### 3.2.2.2 Standards needed

Guaranteeing that AT developed or purchased by an institution is safe and of good quality is often not easy to determine. For many products worldwide, this is guaranteed by the presence of specific standards that need to be met to receive appropriate certification. However, currently there are no globally accepted specification and standards for many AT. Many stakeholders felt that this represented a significant barrier to the access of effective and appropriate AT. Global standards were seen as essential by many and thought to play a crucial role not only in simplifying procurement from third parties, but also in potentially facilitating the development and exportation of good quality AT that are produced in LMICs.

Standards do exist in some areas. Those mentioned included the ISO structural testing for lower limb prosthetics, which were described as "could be improved but the current standards are usable enough" and as a "good approximation for durability and longevity (low maintenance needs)". However, concern was raised over the "15k-30k USD to have an ISO registration", which could prevent innovations from being tested. One suggestion for making product standards more accessible was to "establish LMIC-specific quality standards (e.g. "CE Mark Plus") and mechanisms to ensure compliance".

It was noticeable that many people working in the development of inclusive education resources were unaware of the DAISY and WC3 standards. It was shown that on occasion people "were following the

rules without knowing what they were"; in other words, they were copying examples they had found which they believed were good without realising the standards which lay behind the creation of the accessible content. Therefore, alongside the standards themselves, it is necessary to ensure people are aware of the standards and have easy-to-follow guidelines which can help them to develop accessible content.

#### 3.2.2.3 Creating a critical mass of innovation

As highlighted by many stakeholders, most mainstream AT in high-resource settings is designed, developed and sold by large private companies. However, the diffusion of products via large private companies in LMICs is extremely low.

Smaller NGOs, charities, maker communities and individuals all over the world are employing their creativity and skills towards the production of innovative design for open-source AT. A number of these design concepts, featuring low-cost materials and requiring no complex manufacturing, have specifically been formulated for use in low-resource settings (LRS). Whereas some of these devices have already been successfully developed and implemented in various contexts, their uptake is still considerably rare. The main challenge to a more substantial diffusion is represented by the fragmented nature of the available information. Open-source design for AT are sometimes deposited in repositories that are popular within the makers community (e.g. Thingiverse, Instructables), other times they might be available, either freely or upon request, on the website of the organisation that developed them (NGOs, charities and research groups). Furthermore, blueprints are not always coupled with the necessary information for easy replication by other parties. Many of the stakeholders interviewed highlighted the need for an appropriate sharing platform specific to AT where these design ideas could be easily found, modified for the user and their context, and recirculated to further facilitate future applications.

Programmes which include the maker movement alongside and integrated with the healthcare system is seen as having 'huge potential'. This was closely linked to the creation of open-source repositories and libraries. The absence of such an open library is seen as a "big issue" in the development of a substantial grassroots innovation movement, but also the establishment of generic APs which could then be "localised and translated for local cultures".

#### 3.2.3 Provision

"An absolute red flag would for example be a one-off action of distributing AT for free, no matter how well meant and strategically planned it is."

#### GATE Member

#### 3.2.3.1 Need for a sustainable approach

AT development and provision is not a one-off activity. Providing a person with an AT is an end-to-end process beginning with screening activities and encompassing assessment, selection, fitting, user training, follow-up and maintenance. For this reason, all stakeholders expressed strongly that provision of AT should be delivered primarily "within the health care system and the health insurance scheme to ensure universal healthcare coverage". The enthusiasm for universal healthcare coverage was in stark contrast to practices such as one-off distribution camps: "[The] entire value chain does not happen in LRS, causing people to abandon prosthetics. Either 'mass fitting' camps that don't

address needs of customers, or high-cost services that people cannot access. Better systems need to be developed to improve outcomes".

Interventions aimed at improving access to AT need to be sustainable in every aspect. The AT workforce needs to be able to fit the AT and provide adequate training to the user. Similarly, parts and materials for eventual repair need to be available to skilled technicians *in loco*. Ensuring continuity of the service at every step is extremely challenging, as it requires coordination between different services, but is also the only successful approach to AT provision.

#### 3.2.3.2 Fragmented services

As reported by the stakeholders, a "major challenge is that most services available are in the central region". Users in rural communities are not always aware of these centres and, even when they are, the difficulty of travelling significant distances, potentially multiple times, to attend the multiple sessions that might be necessary for the provision of an appropriate AT can discourage them from accessing the services.

The problem of distance and lack of local resource is also true of inclusive school environments, with children needing to travel over 80km to at the beginning and end of each week to attend an inclusive boarding school. It's noteworthy that this journey could have been made once a term if the mother of the child had been able to afford weekend boarding fees.

In other contexts, members of the AT workforce might travel in the community to assess and provide AT to users living in remote areas. However, services provided in this fashion are often erratic and do not guarantee the same level and continuity of service available in urban locations. Even when satellite development and provision centres are available in the community, these secondary centres often lack both staff and physical resources, which negatively affects the quality of the services provided.

Many stakeholders also commented on the necessity of service delivery standards. The wheelchair provision standards, which were developed by the WHO, were consistently praised as a model, as was the Exceed Worldwide model. Similarly, the standardisation of International Society for Prosthetics and Orthotics (ISPO) training and accreditation of clinics was praised when available, "but often countries will have a few ISPO-certified locations, with the remainder only being certified with local standards (e.g. India)".

It was acknowledged that healthcare systems are not the only route to provision of AT. UNICEF, for example, are one of the largest procurers of AT for children, and in many countries, eyeglasses are privately purchased outside of the healthcare system.

#### 3.2.3.3 Donor dependent supply

Another important barrier to the continuity of AT provision services in many LMICs is related to the heavy dependence that is placed upon a donor-based supply chain. Many stakeholders highlighted how only a few AT in each country are often provided through a more stable chain of local manufacturing and/or commercial procurement of imported goods. On the other hand, the supply of most AT is almost entirely dependent on donations made through charities and NGOs. Firstly, reliance on donor-based supply chains poses severe concerns related to the quality of AT. Many AT provided by donors are of low quality and not appropriate to the local context. Secondly, donor-based supply chains are often erratic, preventing the delivery of reliable services. Finally, reliance on a donor-based supply chain often results in the provision centre being without the appropriate stock of spare parts that might be needed for AT maintenance.

The donor-dependency is exacerbated by a lack of resources within hospital settings:

"All regional hospitals are meant to be fabricating devices but do not have the funding to do this. The main hospital providing services and fabricating devices is Mulago National Referral Hospital. Most devices fabricated are for mobility disabilities. See few wooden or metal crutches. [In a] recent trip to Eastern region found that regional hospitals did not even have tool boxes to fabricate devices. For example, at Mbale Hospital there were four rehabilitation technicians, but they were not fabricating any devices."

This leads to "Other organisations donate second hand wheelchairs (such as Rotary), but these are not provided through services and there is no access to spare parts for repairs".

#### 3.2.3.4 Low demand means high cost

The high fragmentation of the AT development and delivery system in many LMICs poses a significant challenge in relation to the implementation of cost-effective strategies for the procurements of both manufactured AT and raw materials for AT development. Many AT development and provision centres in LMICs are small and have limited resources available. Low demand for AT and materials made to suppliers result in much higher cost per-unit, mainly due to higher shipment costs. Many stakeholders suggested that the use of a hub-based approach, where several centres, coordinated by regional or national offices, estimate their need for AT and materials, pool together resources, and make collective orders to lower the cost per unit of AT and materials supplied which could help mitigate the effect of the problem.

This approach was taken to another level by some stakeholders who insisted the only way to ensure universal access to AT was to begin to shape the market, specifically to: "Demand forecasting to demonstrate volume to suppliers", "drive disruptive innovation for service delivery models and use of technology (e.g. e-health solutions)", and "Ensure innovative/new service delivery models are integrated into private health care and/or other access points (e.g. pharmacy chains, etc.)".

Finally, it was believed that increased "budgets and investments" were necessary to create a stepchange in the 10% market diffusion currently available globally.

#### 3.2.4 Personnel

Trained professionals are not being absorbed into services. Services are not growing at the rate expected. Services are low quality and graduates are not motivated to work in the services.

AT professional, Tanzania

#### 3.2.4.1 Expanding current AT workforce

Currently, many AT service delivery models are dependent on the availability of highly qualified professional staff. This means that in many LMICs, the number of trained professionals is simply not sufficient to cope with the incredibly high demand for AT design, development and provision. Some stakeholders reported that the current education system in their countries lacked the resources to provide sufficient third level qualifications for the required number of healthcare professionals. In several cases, young people therefore needed to travel to neighbouring countries to obtain the qualifications necessary to work in the AT sector. On the other hand, other stakeholders stated that many students who graduated from professional courses were unable to find a satisfactory occupation, suggesting that the solutions required for AT lie in developing systems approaches which

are beyond the simple expansion of currently available courses. An additional problem of "Brain drain of professionals moving away from low-resource settings/countries or to urban areas" was reported.

To improve AT access in a more cost-effective manner, stakeholders suggested the potential of delegating, where possible, tasks related to the development and provision of AT to less specialised personnel. Furthermore, several stakeholders advocated for the abandonment of the siloed approach (where one professional is only trained to provide one type of AT) through the integration of more comprehensive AT training in new and currently existing curricula.

#### *3.2.4.2* Harnessing the power of technology

Many stakeholders felt that technology, in particular mobile technology, could represent a powerful tool in improving the capacity of personnel involved in AT development and provision. Some stakeholders proposed the use of digital technology to provide global, responsive and up-to date training of non-specialised personnel to facilitate the development of skills necessary to develop and provide AT. Others suggested that mobile apps could be used to facilitate screening and AT assessment in primary healthcare settings. Technology could be also used to train and support caregivers who were seen by many stakeholders as valuable, but often overlooked, additional AT personnel.

#### 3.2.5 Continued development of trained staff

Clinical staff complained about the lack of access to continued training. They might receive specialist training over 1-2 days from experts who fly in from high resource settings such as the UK or USA. However, these were "one-time shots" of information and there was little opportunity to follow up or to further expand knowledge. Budgets for training, such as attending international conferences and workshops, were extremely limited and all clinical staff spoke of a desire to learn more and to be better informed. There was also discussion regarding how to formalise career paths for AT personnel.

#### 3.2.6 Policy

"Recognise that it will take a significant effort and level of resource to make a big difference, so a consortium approach is required"

Research interviewee

#### 3.2.6.1 Lack of coordination

The provision of AT is a complex process that requires complex interventions at different levels. Due to the limited amount of available resources coordination amongst the various parties involved is crucial. Currently, lack of coordination of all the parties responsible for the development and delivery of AT results in decreased efficiency of many programmes, with increased cost and an uneven distribution of the AT network across the territory. Stakeholders considered of primary importance the establishment of comprehensive policy framework that could be used to build effective coordination between different ministries at government level (e.g. Health, Education, Social Welfare, and Finance). Furthermore, as much of the current AT provision in LMICs is carried out by NGOs, engagement and collaboration between government, non-government agencies and other institutions is of primary importance to ensure effective coordination and maximise the results of the interventions implemented. Many stakeholders felt that policies that facilitate a collaborative hub approach within countries, and even regions, would yield greater potential towards improving access to AT.

#### 3.2.6.2 Policies without implementation

As reported by the stakeholders, many countries had overall policies in place to facilitate access to AT. However, some polices are incomplete (e.g. only few AT are included in national insurance policies while others are excluded), whereas others are very general, lacking the level of detail necessary to their successful implementation (e.g. a policy on wheelchair provision without links to rehabilitation services). Many governments have ratified the UNCRPD, but few are meeting their obligations. National legislation should be encouraged to embed meeting these obligations in day to day operations and budgets. Global guidelines for policy implementation were often advocated for. Nonetheless, global guidelines should allow for sufficient room to develop different strategies as a particular country's situation will often be unique.

#### 3.2.6.3 Legislation to facilitate rather than hinder

Stakeholders felt that legislation could play an important role in ensuring access to AT of appropriate quality across different countries. However, excessive bureaucracy can become a significant barrier to the development and delivery of AT. For example, the frequently-high cost and long times needed for government approval when new AT are developed within a country can ultimately discourage development, particularly from smaller enterprises that might have reduced resources. Similarly, many countries have unclear regulations regarding the taxation to be applied to AT or the materials needed to develop AT, which can create considerable problems when attempting to estimate the cost of new interventions from various organisations.

#### 3.2.6.4 Funding clarity

Despite the presence of policies related to the development and provision of AT, many countries do not appear to have specific budgets allocated to AT. In some cases, some AT are issued under insurance schemes, but more often the system relies most heavily on donations from international agencies, NGOs and charities. In some countries, a few AT are provided under government budget, but the rules around the selection of AT and the allocation of the budget amongst different centres are unclear. Stakeholders advocated for a more effectively managed funding system which is clear and transparent for all parties involved.

#### 3.2.7 Other

#### 3.2.7.1 Creating networks of disabled people for support, advocacy, and to promote awareness

Disability often makes life vastly more challenging for the person affected and can lead to social isolation. Many of the stakeholders involved in the various scoping activities recognised that facilitating the creation of responsive and coordinated communities of disabled people could lead to important benefits for the people involved and society as a whole. Interacting with other people who have similar disabilities can help a person to receive information on AT and access to services that might facilitate integration in education or employment. Where possible, users might be able to provide peer training for AT use, thus reducing the need for user training from healthcare personnel. Moreover, communicating with other individuals with disabilities can simply help people to feel connected and reduce the chances for social isolation. Finally, close-knit communities of disabled people might be able to advocate more effectively for their rights, including the right to access appropriate AT.

#### *3.2.7.2* Need for an accessible environment

All stakeholders agreed that access to appropriate AT is of crucial importance for the independence of many disabled people. However, as it was pointed out several times, access to AT is not a sufficient condition for independence. An inaccessible environment can prevent or limit the use of AT. For

example, the physical inaccessibility of roads and public transport around a person's house can make a wheelchair practically useless as the person would still be unable to leave the house.

#### 3.2.7.3 The power of mobile and internet connectivity

Mobile phones and Internet connectivity were mentioned as opportunities which needed to be maximised. Tools such as the PEEK (<u>https://www.peekvision.org</u>) eye health diagnosis tool were highlighted as innovations in the field of screening.

Mobile was also seen as a way to enable disabled people to gain access to information and facilitate better sharing of best practice. It was also felt by some interviewees that mobile could be harnessed to help disabled people form collectives to campaign locally for their rights.

Hearing was mentioned on more than one occasion as an area ripe for utilisation of mobile and connectivity, with the possibility of hearing assistance given over the internet, and mobile seen as a way of driving down costs.

#### 3.3 Emerging themes

Thirteen themes emerged as a direct result of the interviewees responses (see Figure 9) and were iterated with stakeholders before being grouped for further investigation.



Innovation in products



AT for humanitarian response



Inclusive innovation spaces



Maximising mobile potential



Vision for a Nation as a model



Integrated mobility aids services



Building global capacity



Finance and policy structures



Digital skills for all



AT distribution hubs



Innovation Challenge Fund



Future casting



Measuring impact

Figure 9: Initial 13 themes which emerged from the interviews

These themes were iterated with stakeholders, and further developed into five areas, which it was felt warranted further research. A methodology for further investigation was then developed for each of the themes. The themes and the decisions on how to further develop them to be able to suggest possible strategies for future investment to unlock the AT market place conclude the first section of the research report.

#### SCOPING RESEARCH REPORT ON ASSISTIVE TECHNOLOGY



Figure 10: The five emerging themes

The five themes which emerged initially (see Figure 10) were: accelerating innovation; harnessing mobile & ICT; building blocks for AT provision; market shaping foundations; research, impact and coordination.

#### 3.3.1 Justification of final themes

- Accelerating innovation incorporated the following initial themes: innovation in products, AT for humanitarian response, innovation challenge fund, inclusive innovation spaces, elements of digital skills for all and maximising mobile potential. Initially maximising mobile potential had been its own theme, however on reflection it was thought to make more sense to fold this into 'accelerating innovation' and to pull out more explicitly the need to build capacity of disabled people.
- 2. Build Community Capacity and Participation. Cutting across each of the initial 13 themes was the need to ensure AT users are involved and leading at every level of the project, and the need to build community capacity to enable more engagement with AT users; both to enhance outcomes and to reduce stigma. As a result of stakeholder workshops and discussions, and the research findings, we conclude that there is a need to explicitly draw out the issues around participation and community capacity directly.
- Building blocks for AT provision elaborated on mobility aids and services by defining the infrastructure needed for AT provision to be possible, including: personnel training, product specifications and service provision guidelines. It also includes elements of harnessing mobile and ICT with regards to tools development for measuring the need and development of new training methods.
- 4. **Market shaping foundations** incorporates finance and policy structures, vision for a nation as a model, AT distribution hubs.
- 5. **Research, impact and coordination** incorporated measuring impact, and evolved to include the idea of harnessing the global momentum in AT provision into a more formalised coalition.

The basis and evolution of these final themes is given in Table 1.

#### Table 1: basis and evolution of the five emerging themes

Accelerating innovation	Building blocks for AT provision
Basis	Basis
<ul> <li>a. AT innovation can disrupt some of the structural barriers and inefficiencies related to ideation, manufacture, procurement, workforce and provision of AT</li> <li>b. AT innovation can help break down/lower barriers of entry, therefore levelling the playing field for new players in AT markets</li> </ul>	<ul> <li>a. increased awareness about AT – need and benefits (especially at the policy level)</li> <li>b. disruption of current models of AT workforce/provision</li> <li>c. less fragmentation/silos and therefore easier access for users and at a lower cost</li> <li>d. better alignment/consolidation of</li> </ul>
<ul> <li>c. Incentivizing innovation can improve accessible solutions by laying the foundations for system- level changes</li> </ul>	global efforts to improve access to AT e. increased evidence-base through collection of comparable data (if WHO tools are used)
<ul> <li>Evolution</li> <li>Innovation programme evolved from <ol> <li>Innovation in products</li> <li>AT for humanitarian response</li> <li>Future casting</li> <li>Innovation challenge fund</li> <li>Inclusive innovation spaces</li> <li>(elements of) digital skills for all</li> <li>(elements of) maximizing mobile potential</li> </ol></li></ul>	<ul> <li>a. Mobile technology can help break some of the structural barriers in AT innovation, procurement, provision, etc. through: <ul> <li>Ability to capture QoL measurement from mobile</li> <li>Deep dive capture of AT outcomes from using mobile</li> <li>Robust method of using mobile data to measure outcomes</li> </ul> </li> <li>Evolution Market Shaping Foundations programme evolved from</li> </ul>
Lovel of Discussion	<ol> <li>Vision for more than one Nation</li> <li>Integrated mobility Aids Services</li> </ol>
12345	12345
Research, impact and coordination	Market shaping foundations
<ul> <li>Basis <ul> <li>a. The lack of robust evidence on need for and impact of AT is preventing the market from scaling</li> <li>b. Evidence is also lacking on how community lod initiatives are driving</li> </ul> </li> </ul>	<ul> <li>Basis</li> <li>A. Improving availability and affordability of AT</li> <li>B. By lowering prices, increasing market info and balancing risks</li> <li>C. Sustainable markets for AT</li> </ul>
change	suppliers

- Robust evidence on what works, when and where it works is essential to ensure AT provision for all
- d. Coordination of the increasing number of initiatives to tackle AT globally is needed
- e. Further momentum building is also required

#### **Evolution**

Research, impact and coordination programme evolved from:

- 1. Measuring impact
- 2. Harnessing the global momentum (note: this is a new theme)

### Level of Disruption: (1)(2)(3)(4)(5)

#### **Evolution:**

Market shaping foundations programme evolved from

- 1. Alternative finance and policy structure
- 2. AT distribution hubs

### Level of Disruption: (1)(2)(3)(4)(5)

#### **Build Community capacity and participation**

#### **Basis**

- a. Community-led practice is under-researched, and we think there might be solutions which could scale, which are not yet understood
- b. User involvement in the design of products, programmes and services leads to better outcomes and solutions
- c. Part of the reason stigma and discrimination continue to perpetuate so perniciously is because of the structural and systematic exclusion of AT users – without role models, leaders, community health workers and politicians who themselves use AT, these issues are never likely to be overcome.

#### **Evolution:**

Build community capacity and participation programme evolved from all 13 themes; it was pulled out into its own theme following stakeholder consultation.

Level of Disruption: (1)(2)(3)(4)(5)

#### 3.3.2 Discussion and conclusion

The five themes create a powerful combination of activities; taken together they represent a framework, one which has emerged from the voices of key global stakeholders.

To test these assumptions, further deep dive investigations were undertaken in East Africa, with a specific focus on Kenya. To do this the research team was expanded to include the Clinton Health Access initiative (CHAI) and Boston Consulting Group (BCG).



Figure 11: WHO/SEARO/Vismita Gupta-Smith

"While there are varying levels of AT market development across countries, key barriers are common across all countries."

USAID-funded market shaping report

# 4 Secondary research and deep dive analysis

After the initial round of stakeholder consultations, several trips, deep dives, and workshops were conducted to answer our second research question:

How should DFID, in partnership with others (including particularly other donors) best direct its intervention toward overcoming barriers to access to AT?

The Global Disability Innovation Hub (GDI Hub) sent a small delegation to Kenya and Uganda between the 5<sup>th</sup> and 17<sup>th</sup> April 2018. The aim was to scope the state of play of the AT market on behalf of DFID in the UK, and to consider whether a joint intervention, led by East African partners, could create a significant shift in the landscape of AT globally. A second trip to East Africa occurred from May 21<sup>st</sup> to the 25<sup>th</sup> to attend the Kenya Mini Disability Summit.

The results of the two strands of research are presented in this section.

First, the initial country deep dives. These investigated the Ethiopia, Kenya, Malawi, Tanzania, Rwanda and Uganda markets across the following domains: products available, services available, finance available, training available to support service provision, policy context (enabling environment).

Results are presented in the form of matrices covering the following products (across each of the domains): manual wheelchairs, walking aids, prosthetics (lower limb), spectacles, white canes, behind ear hearing aids, PDAs.

Second are the results of a more detailed, Kenya-focused scoping study, where the availability of various assistive technologies was investigated. This was followed up with an "Innovation scoping exercise" in Kenya, the results of which are given in Appendix 2.

Additionally, a USAID-funded market shaping exercise was conducted by BCG to better understand current market shortcomings and barriers to uptake for two prioritised APL products. The results of this contribution are given in Appendix 3.

Finally, during this time, CHAI conducted market shaping deep dives in spectacles, prosthetics, orthotics, and PDAs. The results of this contribution are given in Appendix 4.

#### 4.1 East Africa deep dive

#### 4.1.1 Summary

An overview of AT provision in East Africa was conducted to attempt to capture the diversity of policy and practice which is currently in place across this geographical region. This region was chosen as it had been thought of as a possible site for a global intervention, through the creation of a regional distribution hub. The idea of a regional distribution hub evolved into one for innovation through multiple stakeholder meetings and workshops as well as discussions at the Global Disability minisummit in Kenya.

The information presented in the country matrices is taken from primary interviews with informants and secondary documentation regarding the policy environments in each country. It is important to be aware that information from these primary interviews is subjective and reliant on one key informant in each of the six countries. Care must therefore be taken not to infer that this is the complete picture at a national or regional level.

#### 4.1.2 Methodology

Both primary and secondary methods of qualitative data collection were used. Secondary data collection involved a search of key databases for the most recent articles addressing the availability of assistive devices and policy context in the key countries.

Primary data collection involved interviews (via Skype) with key people working in the sector in the selected countries. Referral sampling (snowballing) was used to identify key informants. Referral sampling is the chosen method so that key informants can be quickly identified within constraints of time and resources. Interviews were semi-structured, using a topic guide to ensure all identified assistive technologies and areas are covered. The data was analysed thematically and is presented in country specific matrices, which can be found in Appendix 1:

- <u>Table 8: Ethiopia deep dive results</u>
- <u>Table 9: Kenya deep dive results</u>
- Table 10: Malawi deep dive results
- Table 11: Rwanda deep dive results
- <u>Table 12: Tanzania deep dive results</u>
- <u>Table 13: Uganda deep dive results</u>

#### 4.1.3 Discussion of findings

Overall findings are discussed below according to the areas of products, services, training, finance and enabling environment. There are differences between countries in the levels of development of the areas of products, services and training. However, the overall picture is the same; supply does not meet demand. For example, in Tanzania, whilst training of personnel in P&O and wheelchair technology is well funded and highly developed (to BSc level), services are not supported, and devices are neither well-funded nor readily available in the quantities required. In Uganda, whilst the National Minimum Health Care Package provides funding for the rehabilitation of disabled people, it does not provide for the production or sourcing of devices, or for training in service provision. In Ethiopia, Malawi and Rwanda, there are simply not resources available for products, or services, and in Malawi, training is limited to physiotherapy.

Significant work is needed to increase the availability of products, services and training, so that all areas work together to provide AT through a comprehensive system.

It is important to note that according to this initial review, there is limited information on the availability of assistive technologies (AT) for visual and hearing impairments, and notably personal digital assistants. Whether this is related to the area of expertise of first tier key informants, or the general lack of availability of these AT, requires further exploration.

#### 4.1.3.1 Products

In most countries there is (some) local production of AT, however, this is limited to mobility devices (wheelchairs, walking aids and prostheses). Even in countries where mobility aids are being produced in-country, supply is heavily supported by importation as production levels are low.

Generally, hearing aids, spectacles and even white canes are imported. It was noted that despite their simplicity in design and use, white canes were not as readily available as they could and should be. Similarly, spectacles were not available as they could and should be. Hearing aids seemed to be less available across the countries, possibly due to a lack of specialists and training in the countries reviewed.

Across all six countries, personal digital assistants were not seen to be available and only noted to be accessed by those with significant financial capacity, who can afford to purchase from outside the country.

As noted in the introduction this review does not take quality of locally produced or imported AT into account.

#### 4.1.3.2 Services

Across the countries, there does not appear to be coordinated systems of service provision. NGOs seem to provide services where government provision is limited, and the private sector seems to dominate in the areas of spectacles and hearing aids. This review did not explore what is meant by 'service' provision and the quality of this and would require further exploration.

#### 4.1.3.3 Training

Across the countries, training available in-country often seems limited to physiotherapy, and in some countries occupational therapy and P&O. Training available in Tanzania at TATCOT is notably more advanced than that available in any of the other countries. Training on other AT, specifically spectacles and hearing aids, does not appear to be widely available, especially hearing aids where ENT specialists seem few.

#### 4.1.3.4 Finance

Apart from Kenya, and some National Insurance contributions in some countries, financing AT and services appears to be a major issue. Government funding seems lacking and support of AT and service providers therefore seems to predominantly fall onto NGOs and INGOs, seeking funding from the donor community. Even in Kenya where funds have been established, NGOs remain major stakeholders.

#### *4.1.3.5 Enabling environment*

Across the countries there seems to be a good enabling environment in terms of policy. However, the implementation of policies and infrastructure to enable this (finance and resources) is the limiting factor. Most notably in Rwanda, where the Government is aware of what it needs to do, the Government is very supportive of initiatives to provide AT, however, without funding and capacity are unable to meet the need for AT and services.

#### 4.1.4 Evaluation of scoping review

This initial scoping review has given an overview of the situation across the six countries; however, a more detailed analysis of each country would be required to verify information and build a more indepth picture.

Time limitations excluded the possibility of in-depth examination of secondary data and policies available in each country. This would be recommended to verify the provisions relating specifically to AT provision.

Time limitations also excluded the possibility of gathering further interviews with second tier key informants, which would ensure more robust primary data.

#### 4.2 Kenya: second sector scoping study

The purpose of this Kenya-focused scoping study is to assess the availability of the following Assistive Technologies (AT) in Kenya, as defined by the World Health Organization (WHO) Priority Assistive Products List (2016):

- Walking aids
- Manual wheelchairs
- Prosthetics (below knee).

The study also considers the availability of mobile phones, networks and internet.

Information was gathered and organised according to:

- Products available
- Services available
- Finance available
- Training available to support service provision
- Policy context (enabling environment)
- The presence of, or extent of, demand-led innovation (if and how ideas from the field are translated into new products and services and the role disabled people take in this process).

The study also details the national, regional and international agencies involved in the provision of the AT.

#### 4.2.1 Methodology

This scoping study employed qualitative research methods to gather data through interviews with key informants. Qualitative interviews were used to gather primary data from the 22 key informants. All interviews were face-to-face, using a semi-structured interview framework.

Questions were designed to gather a range of factual information (e.g. what exists) and qualitative, value-driven information (e.g. what barriers are faced). This was to optimise the range of information gathered within one interview.

The interviews were not recorded due to time implications of transcription, but notes were taken which then formed the basis of all subsequent data analysis.

Five regions of Kenya were identified using population statistics to select the regions that best represent the country. Population in the five regions cumulatively represents 50% of the population of Kenya. The five regions include:

• Central

- Western
- Eastern
- Coastal
- Rift valley

Within these five regions, organisations were identified at county level through purposive sampling to quickly and efficiently identify key informants best able to supply the required information due to their involvement in AT provision, specifically prostheses, wheelchairs and walking aids.

A total of 22 key informants were interviewed across the regions, as shown in Table .

Table 2: Study informants

Region	No. of organisations	% of organisations
Central	11	50%
Coast	4	18%
Eastern	1	5%
Rift valley	2	9%
Western	4	18%
Total	22	100%

The predominance of organisations in the Central region relates to the concentration of organisations in the capital of Nairobi and reflects the distinct regional imbalance in the availability of AT across the country.

The range of organisation types is detailed in Table and shows the predominance of government hospitals (55% of organisations selected). This also reflects the predominance of government hospitals in the provision of AT across the country. Faith based centres and hospitals are also key providers, alongside NGOs. Only one key informant from a Disabled People's Organisation (DPO) was included in the sample.

Table 3: Range	of organisations sampled	

Organisation type	No. of organisations	% of organisations
Disabled People's Organisation	1	5%
Faith based centre	3	14%
Faith based hospital	1	5%
Government hospital	12	55%
Government training institution	1	5%
Ministry	1	5%
Non-Governmental Organisation	3	14%
Total	22	100%

#### 4.2.1.1 Evaluation of research methods

The chosen research methods for this review demonstrated the following key strengths:

- Interview questions were developed to cover the specific information required
- Different types of questions were used to elicit a range of information including factual and value-driven

• A range of information from a range of sources (key informants) could be gathered within a short timeframe.

However, several factors may have produced bias in the findings including:

- Subjectivity of key informants and opinions gathered
- Bias inherent in purposive sampling and identification of key informants.

Please also note that the quality of products, services or training has not been assessed in this study and all information is based on subjective responses of informants.

Additionally, the low representation of disabled people in the sample of key informants (including only one from the DPO) could be an indicator of the low representation of disabled people in the provision of AT. This is supported by findings in section 3.2.1.3 of this report and indicates that any further study should actively seek and include the views of disabled people.

In terms of the design of the interview, a pilot would have revealed that some questions were open to a degree of interpretation by the informant, meaning that information gathered was not consistent. Narrowing some of the interview questions would have helped in this regard.

#### 4.2.2 Results

Interview notes were transferred to a database (Excel) to categorise responses and analyse emerging patterns and themes. A top-level summary of results is shown in the matrix below (Table 4).

#### Table 4: Results of a sector scoping study of Kenya

Kenya	Products	Services	Training		Finance	Enabling environment	Demand-led innovation
Prosthetics	Local products are available, using imported components. Imported products are not available.	There is a high proportion of services in the Central region (and capital of Nairobi). Services face a range of barriers, primarily funding, resources and	Most organisa (>90%) have t personnel in c technology, p or rehabilitati	ations crained orthopaedic rosthetics on.	Most funds for products and service provision are provided by: user contributions, county government and donors (including International donors). Other sources included national	Policies tend to be in place at a national level but not at a regional/county level. The implementation of policies at a regional/county level also seemed lacking with	Barriers to carrying out robust and consistent follow-up (including funding and distances between users' locations and the service centre) inhibit the flow of communication between
Wheelchairs	Local production is limited. Only one organisation reported producing wheelchairs. Others reported imported wheelchairs available in pharmacies.	personnel.	In relation to fewer organis (<50%) have t personnel in v service provis	prosthetics, ations rrained wheelchair ion.	<ul> <li>government, NCPWD, volunteers (gifts in kind) and trading.</li> <li>Product costs are often supported by user- contributions, personnel costs by county government and other service, training or follow up costs by donors. It was also noted that trainees supported their own training costs. Common barriers to accessing finance included barriers relating to cost or finance, awareness and attitudes and policy.</li> </ul>	some lack of clarity on accessing such provisions as the funds provided by the National Council for Persons with Disabilities.	service user and service, and the involvement of users in translating ideas from the field to new products and services was minimal. Many barriers to new innovations were cited, predominantly funding and exposure to new technology and ideas.
Walking aids	Local production is available but generally limited to crutches. Imported walking aids available in pharmacies.		See above.				
Phone & internet networks Phones Interne public.		Phones and Internet is av public.	nones and phone networks are available, but not to all, and often not to service users. Iternet is available, but this is generally limited to organisations, and less available to the ublic.				

#### 4.2.3 Products

Overall informants reported a higher ratio of locally produced products to imported products. See Table for details. A further question would investigate why this is, whether due to the cost of imported products and importation, availability and knowledge of products, or the nature of products imported (predominantly wheelchairs).

	No. of	% of
Ratio of local to imported products	organisations	organisations
Higher ratio locally produced	13	59%
Higher ratio imported	6	27%
N/A	3	14%
Total	22	100%

Table 5: Ratio of local to imported products

#### 4.2.4 Services

#### 4.2.4.1 Service availability

Key informants in only three of the five regions cited a number of services available in their county, and these were predominantly hospital-based services. These were: Central, Coastal and Western. It is unclear whether this indicates a lack of services in the Rift Valley and Eastern regions, or whether this was rather due to a lack of information gathered as a result of misinterpretation of the question. What is clear, however, and reinforced by statements by informants, is that there is a high proportion of services in the Central region (and capital of Nairobi).

#### 4.2.4.2 Limitations to service availability

When asked about the limitations faced by the services, nearly 50% of responses related to three primary issues, including:

- Funding/cost (23% of responses) including available budgets in organisations, funding streams and high costs of products and materials
- Resources (22% of responses) including facilities, materials, infrastructure
- Personnel (9% of responses) including number of available staff

Other limitations cited more than once (totalling 32% of responses) could be termed secondary limitations, including:

- Expertise of staff
- Inappropriate products available
- Accessibility of service and distance users must travel
- Awareness of service amongst users
- Poverty of service users and their ability to contribute to costs
- Capacity of staff and resources
- Low priority of service provision at management level and governmental level
- Overwhelming need
- Stigma attached to disability and the bearing this has on prioritisation

It could be suggested that all the secondary limitations cited impact on the primary limitations and could form the basis of problem tree analysis in a further study.

#### 4.2.5 Training

#### 4.2.5.1 Training received by staff at the organisation

In terms of the training received by staff at the organisation, responses from key informants showed that more services had trained staff in orthopaedic technology/prosthetics than wheelchair technology:

- 20 informants (or 91%) reported having staff trained in orthopaedic technology, prosthetics or rehabilitation (from Kenya Medical Training College or the Tanzanian Training Centre for Orthopaedic Technologists (TATCOT)). Only 2 informants (or 9%) reported not having staff with such training.
- Nine informants (or 41%) reported having staff trained in wheelchair service provision (including the World Health Organisation Wheelchair Service Training Package (WHO WSTP) at Basic and Intermediate level). 13 respondents (or 59%) reported not having staff with training in wheelchair service provision.

Other training included:

- Short courses
- On-the-job training (including in-house training on Appropriate Paper Technology)
- Management training

#### 4.2.5.2 Availability of training at county/national level

When asked about the availability of training at county level, 7 informants (or 32%) reported that no training was available at county level. However, only 2 (or 9%) reported the availability of any specific training at county level (both in the Coastal region). All other informants report training available at national level, in the Central region. This includes: training at Kenya Medical Training Centre (including Prosthetics, orthopaedic technology and walking aids) and WHO WSTP Basic and Intermediate training. It could therefore be inferred that training availability is concentrated and not devolved, predominantly available centrally.

#### 4.2.5.3 Availability of training for beneficiaries/service users

16 informants (or 73%) report providing basic user training to beneficiaries of the service. Only three informants (or 14%) report no or limited training for beneficiaries. The remaining three (14%) from children-focused organisations report parent/carer training. Some informants also report maintenance training and wheelchair user mobility skills training. Only two informants (or 9%) report offering peer training, whilst others recognise it as an unmet need.

#### 4.2.6 Finance

#### 4.2.6.1 Financing products, services, personnel, training and follow up

Responses given by informants revealed the predominance of funds for products and service provision being provided by user contributions (31% of responses), county government (29% of responses) and donors (including international donors) (32% of responses). Other sources of finance included national government, NCPWD, volunteers (gifts in kind) and trading.

It was clear that generally, product costs were supported by user-contributions, personnel costs by county government and other services, and training or follow-up costs by donors. It was also noted that trainees supported their own training costs.

Most informants (18 or 82%) reported that there was no difference between funding for wheelchairs/prostheses/walking aids. However, three informants (or 14%) reported that wheelchairs were donor funded, whereas prostheses and walking aids were not and required user-contribution.

#### 4.2.6.2 Barriers to accessing finance

The barriers to accessing finance given by informants are listed in Table . The barriers were many and diverse, ranging from fatigue (including donor fatigue and staff fatigue in pushing for funding) to lack of awareness and weak stakeholder coordination. Common themes, however, included barriers relating to cost or finance, awareness and attitudes and policy.

	No. of	% of
Barrier	responses	responses
Low priority	13	22%
Lack of awareness	9	15%
Limited funds	7	12%
Bureaucracy	4	7%
Allocation of Department funds based on match funding	3	5%
Lack of clear policy on accessing funds from the NCPWD	3	5%
Users unable to pay	3	5%
Approach to health is curative not rehabilitative	2	3%
Attitudes towards disability	2	3%
Fatigue	2	3%
Focus on service provision in capital by NCPWD	2	3%
High costs of products	2	3%
Lack of policy	2	3%
Unreliable donor funds	2	3%
Weak stakeholder coordination/partnership	2	3%
Lack of community ownership	1	2%
Lack of donor trust	1	2%
Total	60	100%

#### Table 6: Barriers to accessing finance for AT

#### 4.2.7 Enabling environment

Only 2 informants (or 9%) cited policies/provisions at the county level. These included:

- Kisumu County Persons with Disability Act (although the implementation of this act was not confirmed)
- County level registration of disabled people for the provision of AT through the National Council for Persons with Disability (NCPWD)

Informants otherwise reported no policy provisions at the county level. National policies were cited (including the People with Disabilities Act (2003), the National Disability Policy, Kenyan Constitution (2010), and the 'Big Four' Agenda for the Nation 2017 to 2022). Some informants cited organisational policies (such as code of conduct, user contribution and child protection). Only one cited the United

Nations Convention on the Rights of Disabled People (UNCRPD) and optional protocol signed and ratified in Kenya in 2007/08.

From the information gathered it would appear that whilst some policies are in place at a national level, the practical implementation of these is not notable by respondents and/or they do not trickle down to County level.

#### 4.2.8 Demand-led innovation

Defined as the involvement of disabled people (service users) in the development of innovations in products and services, listening to users under the commitment to "leave no one behind", informants were asked about the processes to follow up users and encourage feedback and communication between users and the service. Informants were also directly asked about the role disabled people play in developing services and products.

#### 4.2.8.1 Follow-up

It was evident that funding and the distance between user's location and the service were major barriers in following up users. Seven informants reported carrying out follow-up but only through appointments, which users only attended if they lived nearby or had a problem with their device. Four reported rarely carrying out follow up and six reported not carrying out follow up at all (unless specifically funded). Only five (or 22%) reported carrying out follow up, including through Community Based Rehabilitation (CBR).

#### 4.2.8.2 Communication

Nine informants reported that there is no formal communication in place; five reported making appointments, making phone calls and CBR; two reported communicating through a community contact or group leader and only three reported communicating through face-to-face follow up. Three also reported a 'To Come Again' programme.

#### 4.2.8.3 Feedback

Three informants reported not having any method of gathering feedback; nine reported gathering feedback but not through a formal avenue; six reported gathering feedback through appointments and outreach; only four (or 18%) reported gathering feedback through a formal avenue that is documented.

#### 4.2.8.4 Role of disabled people in developing services and products

Six informants reported that disabled people do not have any role in developing services and products; five reported a minimal role; four defined their role as raising awareness; only three (or 14%) mention disabled people being employed; only four (or 18%) mentioned involving disabled people in the service they receive (having choice in the process), and two refer to disabled people's role to give feedback.

#### 4.2.8.5 Barriers preventing innovations entering the market

Funding was the most cited reason for innovations not getting to the market, followed by lack of exposure to new technology, innovation, and ideas. Table below shows all barriers cited by informants, categorised.

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Barrier	No. of responses	% of responses
Funding	16	21%
Exposure	10	13%
Communication/networking	7	9%
Resources (infrastructure and equipment)	6	8%
Training	6	8%
Awareness	5	7%
Recognition (by management)	5	7%
Skills	4	5%
Government support	3	4%
User feedback	3	4%
Conservative thinking	2	3%
Research	2	3%
Acceptance (by other organisations)	1	1%
Acceptance (of products)	1	1%
Lack of recognition of training	1	1%
Partners support	1	1%
Policy	1	1%
Understanding (of value)	1	1%
Total	75	100%

#### 4.2.9 Mobile phones, networks and internet

#### 4.2.9.1 Availability of mobile phones and networks

All 22 informants reported availability of phones and phone networks. Two reported excellent availability. Six reported availability to be good (or generally good) and the remaining 14 reported it to be available to some of the population – with two organisations reporting availability to 45% and 50% of the population respectively.

In summary, phones and phone networks are available, but not to all.

#### 4.2.9.2 Availability of internet

10 of 22 informants said that access to internet was good/available within the organisation, but not so available outside the organisation. One informant stated that internet was only available to administrative staff within the organisation.

Other informants reported that access to internet is generally available or fairly good. There was a notable difference between one organisation in the Western region reporting that internet was available to 40% of population, and another in the Eastern region reporting that there was only 5% coverage. Could this be a regional difference in development? Only one informant in the Central region reported that access to internet was "not good".

In summary, internet is available, but this is generally limited to organisations, and less available to the public.

#### 4.2.10 Conclusions and recommendations

During the interview, informants were asked to cite key challenges or gaps for AT provision. Whilst informants cited a range of challenges, just under 50% of all responses related to just three key

challenges: lack of funding (20%), resources (machines, tools, equipment, workshop space) (18%) and training (10%). In conclusion, it would be safe to assert that these key challenges were raised in discussion regarding products available, and services, including follow-up (and the resulting lack of involvement of users in translating ideas from the field to new products and services).

Due to the lack of representation of disabled people in this study, it would be recommended that any further study should actively seek and include the views of disabled people.

An "Innovation scoping exercise," which can be found in Appendix 2 of this report, was also carried out by way of follow-up to this part of the research.

#### 4.3 Discussion of findings from secondary research

Market shaping activities are currently not possible, and further analysis is necessary to enable market shaping to take place. There is a range of readiness levels both across countries and products. However, the initial research has begun to map the markets, identifying both key characteristics of the product specific markets for wheelchairs, prosthetics and orthotics, spectacles and hearing aids. However, more work is needed to develop these initial market maps into roadmaps with actionable components. This work will necessitate several months of research to gather the evidence necessary to put forward a plan for market shaping for AT.

There is much to learn from the wheelchair sector. The coordinated effort to deliver wheelchair standards through a Global Consensus Conference has shown what is possible when the AT community works together. A key enabler of the wheelchair standards movement was the GATE community. GATE and the WHO have helped to galvanize a disparate community, and in doing so helped to engage governments in putting AT on the agenda.

There is a clear movement towards grassroots innovation which can be harnessed for AT design, manufacture and repair. This movement can also enable disabled people to learn skills which can enable them to secure high-quality employment.

Finally, Kenya is enthusiastic and engaged in the opportunity for the creation of an AT Innovation Hub within the University of Nairobi. This has the support of the Government of Kenya, NGOs, DPOs, private companies and academia. There is no reason to believe Kenya is alone in this ambition, given the experience of South America (see case study 5 in Annex 2 for an example of this), and a key consideration for the global community as it moves forward is how best to harness the power of the making community, and how this integrates with market shaping activities.

"What we see in research is that almost all efficient programmes are comprehensive. i.e. not focusing on a singled-out service delivery but rolling out (or improving) integrated systems."

- AT interviewee's response during the initial stakeholder interviews

## **5** Recommendations for intervention

What has become clear over the 15 weeks in which this research was conducted is that there is a growing momentum for change with how AT is provided. What has emerged are several ideas for intervention, which, if completed together, have the chance to accelerate the formation of a new global AT landscape. One which understands the role of market shaping both from a supply and a demand side; one which will be built with Nation States and disabled people and one which can ensure we leave no one behind.

#### 5.1 The principles of intervention: designing a normative framework

Given this global context, broad consensus, the commitment of the new Secretary of State and the focus of the Government's Global Disability Summit, there is a real opportunity for DFID to show leadership on the AT agenda, but a global approach is needed to deliver genuinely revolutionary change.

Also, how we do this matters. The approach to AT provision requires an explicit normative framework. We suggest this be 'framed' around the following principles:

- I. A social development approach and political leadership: the priorities for intervention should lead to better outcomes for AT users.
- i. A global, mission-led partnership: this partnership should be more than a donor-led approach, with measurable outcomes and clarity of how to ensure a return on investment. A
target will need to be well understood by all stakeholders and ensure it is possible for many bottom-up approaches to be developed to enable it to be delivered. This must be backed up with research and better data.

- ii. Testing and piloting market shaping as a methodology accepting there is a way to go before there is the opportunity to back this approach at scale, we suggest the development of a research base which is trialled and refined with leaders in the field of market shaping. It is important global leaders spearhead this work, beyond the disability sector.
- iii. Backing market shaping with work on systemic interventions with national governments. The role of the global community to reduce the cost of AT must be carried out in conjunction with national governments, with clear routes for the provision of AT within healthcare, education and other nationally delivered systems.
- iv. Harnessing innovation with a focus on leapfrog technology, looking beyond the traditional understanding of products or services, and bringing in new players.
- v. Community participation and capacity building the exclusion of AT users from programme design, policy and decision-making leads to less good outcomes, continued power imbalances and political exclusion these things are all part of the problem. Any solution must be designed to counter this, through building on community-led solutions with AT users involved at every level of the process.

To tackle the low hanging fruit (increasing the numbers of cheaper products available to those at the easier-to-reach end of the spectrum e.g. eyeglasses to those with slight visual impairments), without focusing on the more complex cases (distribution, the impact of products on well-being; and issues of intersectionality) would be a failure dressed up as success. It is against this framework, therefore, that we think DFID-led interventions should be 'tested' against these priorities.

One possible framing of the new approach to AT provision globally is given in Figure 12.



Figure 12: One possible interpretation of what a global partnership on AT could look like and how it could operate.

#### 5.2 A global mission: to enable a lifetime of human potential

Mission-led innovation has been "behind some of the biggest innovative leaps forward in the last century and can offer the transformative approach needed today" (Mazzucato, 2017). It has emerged as the organising principle behind which significant change has taken place across sectors; addressing global challenges like climate change, public health and demographic shifts. From the mission to put a human on the moon, to the UK Industrial Strategy, to global interventions aimed at improving access to vaccines and immunisation: a common goal, well understood and coordinated, delivered by many, yet drawing on the mechanisms and modes across all sectors, is a model that works (Mazzucato, 2017).

We cannot achieve our Global Mission on AT (however it will be defined) by direct investment and control or all efforts. Partners and stakeholder need to understand how independent, autonomous action can support the global mission.

Moreover, we believe that intervention in this sector is the right thing to do and we know it is essential to delivering the SDGs. But we also think that it will drive innovation in creative and exciting ways, harnessing ubiquitous technology and bringing new actors into the traditional development space. Enabling space for this creativity, for failure as well as success, also requires clarity of purpose.

#### 5.3 A Global Partnership - how can stakeholders contribute and engage?

This is not a single team mission, and achieving the SDGs, the UNCRPD and the WHO Resolution will require a variety of new partnerships and approaches to strengthen and support those tried and tested approaches. To achieve a global AT mission everyone needs to play their part:

- **Donors** (and the innovators within them) need the capacity, political backing and creativity to align their agendas, take a leadership role, and take the risk of making this happen;
- **DFID** specifically, can consider how its investments both within and beyond inclusive development help to meet the needs of AT users, especially through the data and evidence that is generated.
- **Multi-lateral agencies** need to be willing to turn their enormous programmes of work to support the Global Mission for AT;
- Academics and researchers must work together to share their knowledge and shape our thinking in very practical and applied ways;
- **Global agencies** need time to trial and test methodologies and pilot interventions they need to be able to fail as well as succeed;
- **The market(s)** for AT and its actors need to function with fewer information failures (thereby impacting innovation, availability and price), fewer barriers to entry, and a reduction in the principle/agent split.
- **Governments** need information and support to generate a better cost/benefit models for intervention in AT, connected to Social Development outcomes and improve systems;
- NGOs and DPOs need the opportunity to test and scale what works; and
- Users of AT need to have their voices heard throughout the process.

Innovators must and do sit in these different agencies – not just within the traditional product design market. To succeed, we believe there must be a mechanism to encourage and support innovations across sectors, geographies and demographics.

Each of these actors would play a role in the new approach to AT globally.

### 6 Conclusion

Our research has found that the challenge of AT represents a complex web of market and system failure, compounded by a lack of participation from the users with the best knowledge of the issues. This results in a supply/demand mismatch affecting almost a billion people, making AT access one of the most pressing problems facing the global health sector, development agencies, governments, communities and families. Because of poor data on use, need and impact, this 'wicked problem' is largely hidden from view to all but those facing the daily struggles its absence creates.

At an individual, family and community level though, there is no doubt at all about the implications of lack of access to useable, appropriate AT; isolation, economic and social exclusion, poor physical and mental health, and reduced life expectancy. In addition to this social and societal impact, the failure of AT markets to function optimally is also a huge economic disadvantage.

But there is hope for a different future. As has been shown in the interventions in the markets for drugs and vaccines in the last decades, when market shaping is successful, the well-being of communities can be improved, global development goals can be met, and economic benefit can be derived. The question is whether this can work for AT, and the answer is that we are only some way from knowing definitively, but stakeholders and partners are keen to test the hypothesis that indeed market shaping is part of the solution when it goes hand in hand with system level capacity building and support.

The systematic discrimination experienced by many AT users cannot be underestimated. It is clear that any intervention must go hand-in-hand with policies and practices to remove stigma and discrimination and empower AT users to participate at all levels of society – including in the design of programmes to address AT; from the very top down.

Our recommendations, then, reflect the nature, scale and complexity of the issues. This is hard and complex work and will take long term, holistic commitment, resolve and investment to be successful. But there is cause for much optimism given the profile, partners and emerging models of practice available to build upon.

If the global community can get behind a single mission; if donors can pump-prime the innovation needed to create and test the models that work (and live with those that will inevitably fail as part of a disruptive process); and if the global community can fund large scale strategic interventions based on 'what works', there is much hope for success.

The risk is that the challenge of AT is complex, multi-faceted and has been largely obscured from view. For sure, the expertise needed to make low-cost, mass-market, life-changing AT a reality for more people is not held in one place. It lies between the traditional boundaries of innovation, development, disability and market leaders. Creative partnerships of new and established actors – which involve AT users and those running the systems that serve them at all levels – will be critical for success.

## 7 Appendix 1: Country research matrices

#### 7.1 Table 8: Ethiopia deep dive results

Ethiopia	Products	Services	Training	Finance	Enabling environment
1. Manual wheelchairs	Some locally produced and	The Ministry of Health	A Physiotherapy (PT)	Ethiopia does not have any	Signed United Nations
	imported (new and second	(MoH) has no system or	training course is available	National Health Insurance	Convention on the Rights of
	hand) wheelchairs	policy for AT and service	at Gondar University.	schemes.	Persons with Disabilities
	available. Reliance on	provision and it is the	However, graduates are		(UNCRPD) (2007) and ratified
	donations and NGO	responsibility of NGOs,	not being taken on by	Community-based health	(2010). Has not signed the
	support.	except for the Prosthetic	hospitals as physiotherapy	insurance schemes exist	optional protocol.
		Orthotic Centre (POC) in	is not seen as a priority. An	within Ethiopia; Social	
		Addis Ababa, which is the	Occupational Therapy (OT)	health insurance is	Signed other relevant
		only government	course is also being	pending. AT has not been	international and regional
		supported service. POC	developed also at Gondar	explicitly excluded from	agreements. (See Swedish
		struggles with capacity.	University.	benefits package, but	International Development
2. Walking aids	Some locally produced	The Ministry of Labour and	No knowledge of specific	coverage by insurance is	Agency (Sida) 2014 a)
	products available.	Social Affairs (MoLSA)	training available.	limited by availability at	
3. Prosthetics (lower limb)	Some local production of	oversees POC, but it is not	A Prosthetics and	facility level.	AT provision falls between MoH
	prosthetics, but	their remit. It is only at	Orthotics (P&O) Diploma		and MoLSA. The Bureaus of
	predominantly supported	POC that the government	level training course is	There is no specific	Labour and Social Affairs (BoLSA)
	by NGOs, including the	supports staff salaries.	available at the	Government funding for,	are responsible for
	ICRC.		Orthopaedic Technique	or in support of, service	implementation with support
		This is not a sustainable	Vocational & Educational	provision across AT. AT	from regional government and,
		system and cannot be	Training College (OTVETC),	provision is therefore	consequently there is regional
		scaled up.	Black Lion National	predominantly donor	variation.
			Rehabilitation Centre.	driven and NGO	
		Physiotherapy		supported, or available	The 1995 Constitution
		departments exist at most		privately.	recognises the responsibility of
		secondary and all tertiary			the state for provision of
		public hospitals, but it is		Beyond simple	services to disabled people.
		not believed that they are		wheelchairs and crutches,	(Sida 2014a)
		fitting wheelchairs or		AT is not procured by	
		other AT.		Pharmaceuticals Fund and	The National Plan of Action for
				Supply Agency	the Inclusion of Persons with

4. Spectacles	Both locally produced and	Services are available only	Optometrists are trained	(government procurement	Disabilities 2012 – 2021 includes
	imported spectacles are	in Addis Ababa and some	at undergraduate level;	agent).	provision for comprehensive
	available.	major towns.	Medical schools at		rehabilitation services. (Sida
			University of Jimma and		2014a)
		Ophthalmology	University of Gondar have		
		departments exist at	Ophthalmology specialty		The Government has positive
		secondary and tertiary	programs.		legislation in place (especially in
		hospitals.			employment, and education
5. White canes	Locally produced white	Services are available only	No knowledge of specific	]	which has an inclusive education
	canes are available.	in Addis Ababa and some	training available.		policy), however, the systems
		major towns.			for implementation are not in
					place.
6. Behind ear hearing aids	There is limited availability	No knowledge of specific	No knowledge of specific		The Disabled People's
	of hearing aids, which are	services – ENT specialists	training – ENT specialists		Organisation (DPO) community
	all imported.	are few in the country.	are few in the country.		is weak as activities are
					restricted by the 2009 Ethiopian
	Cochlear implants have	Services are provided	Ethio-American Hearing		Charities and Societies
	been donated for a limited	through NGO missions;	Project has begun in-		Proclamation.
	number of surgeries.	one hearing aid clinic	country training of hearing		
		exists in Addis Ababa. ENT	technicians; the first		The most recent School Health
		specialists are based at 3	Masters in Audiology is		Strategy includes recognition of
		tertiary hospitals. Cochlear	expected to begin in 2019.		the need for vision and hearing
		implants have occurred at			screenings in schools.
		2 facilities (5 total implants			
		to date).			
7. Personal digital	These have not been seen to	b be available in the country, h	owever, it was recognised by t	the key informant that	
assistants	assistive technologies (softw	/are e.g. speech to text) is key,	especially in area of education	n. A focus on physical	
	devices only will not meet no	eeds.			
General note: Overall the ne	ed is not being met and this is	s being compounded by rapid p	population growth (The inform	ant said that population is gro	owing by 2 million per year.
According to Index Mundi th	e population growth rate for 2	2017 was 2.85% (https://www	indexmundi.com/ethiopia/po	pulation_growth_rate.html)).	Additionally, there is no
coordination of stakeholders	s in the provision of AT (the wh	neelchair stakeholder group is	inactive) and activities are reg	ionally located.	

#### 7.2 Table 9: Kenya deep dive results

Kenya	Products	Services	Training	Finance	Enabling environment
1. Manual wheelchairs	Locally produced and	The Association for the	NGOs (Motivation) provide	The National Council for	Signed (2007) and ratified (2008)
2. Walking aids	imported mobility devices	Physically Disabled of	training for wheelchairs.	Persons with disabilities of	the UNCRPD & optional
3. Prosthetics (lower limb)	are available.	Kenya (APDK) is the main		Kenya (NCPWD) provides	protocol.
		NGO providing a range of	The Government offers	funding for AT and	
	According to key	services and AT, including	training courses in PT, OT	supports services.	Signed other relevant
	informant approximately	PT, P&O, OT and	and P&O at the Kenya		international and regional
	75% of wheelchairs used	Community Based	Medical Training College,	The National Fund for the	agreements. (See Sida 2014b)
	in Kenya are imported,	Rehabilitation (CBR).	however, recently some	Disabled of Kenya provides	
	with only a very small		private colleges have	funding for AT but	AT provision falls under the MoH
	fraction produced locally.	Other smaller NGOs	started to offer these	provides them directly to	(Division of Rehabilitative Health
		(predominantly faith	courses, especially in PT.	users, rather than through	Services) and Ministry of Labour
	For prostheses, over 99%	based) also provide AT		established service	and Social Services.
	are produced locally	(e.g. Cure and Bethany	PT and OT courses are	structures (funding is	
	although the components	Kids).	available at Degree level.	sourced through	The 2010 Constitution
	and materials are			investment of government	recognises the rights of disabled
	imported.	Private services are also	A P&O course is available	funds in real estate).	people. (Sida 2014b)
		available.	at Diploma level.		
				4	The People with Disabilities Act
4. Spectacles	Imported spectacles are	Services available in	No knowledge of specific		(2003) established the NCPWD
	avallable.	private opticians and	training available.		(2003/4). The NCPVD is settin-
		heapitals of a Kikunu			of Labour Social Socurity and
		hospital and the Liens Eve			Services (Sida 2014b)) and
					engages in policy development
		Hospital.			and implementation to ensure
5 White capes	Imported white capes are	Services mainly available	No knowledge of specific	-	compliance with international
5. White calles	available	through private sector	training available		and regional agreements
		otherwise Kenvan			
		Association for the Blind is			The National Fund for the
		the main provider outside			Disabled of Kenva (2003) was set
		the private sector.			up by the NCPWD.
6. Behind ear hearing aids	Imported hearing aids are	Services mainly available	No knowledge of specific	1	Policies are in place but not
8	available.	through the private sector,	training available.		operational.
		otherwise the Kenyan			
		National Association of the			

		Deaf is the main provider outside the private sector.		
7. Personal digital	Kenya is in the early stages c	l f accessing personal digital ass	sistants.	
assistants				

#### 7.3 Table 10: Malawi deep dive results

Malawi	Products	Services	Training	Finance	Enabling environment
1. Manual wheelchairs 2. Walking aids	Only Queen Elizabeth Central Hospital (QECH) and Malawi Against Physical Disabilities (MAP) have capacity to produce locally but the country is mostly reliant on imported and donated wheelchairs. Most wheelchairs imported are orthopaedic, either procured through the Government (with donor support) or private pharmacies.	Provision of mobility devices is centralised. Only QECH and Mzuzu have the capacity to provide wheelchair services according to the World Health Organisation (WHO) 'Guidelines on the provision of manual wheelchairs in less resourced settings' (2008).	A PT course is available at The University of Malawi, College of Medicine, (Degree level). OT training is accessed outside the country at Tanzania Training Centre for Orthopaedic Technologists (TATCOT) or in South Africa. Training in wheelchair provision has been provided by Motivation, however this is ad-hoc and donor dependent. No specific training	In terms of healthcare provision, the government has budget for areas such as Malaria prevention and purchase of drugs, however, there is not an equivalent budget for AT. AT provision is dependent upon donations from NGOs. Procurement of AT, specifically wheelchairs, is done on a departmental level and is approximately 75% reliant on donations. The Government provides	Signed (2007) and ratified (2009) UNCRPD. Has not signed the optional protocol. AT provision falls under the Ministry for Social Development and People with Disabilities (1988) which drafted the National Policy on Equalisation of Opportunities for Persons with Disabilities (2006) which links to a number of other policies (Lang 2008 p.69), however, there is nothing specific on the provision of AT. The Handicapped Persons Act (1971) established the Malawi
3. Prosthetics (lower limb)	wooden crutches (QECH and MAP) but walking aids are otherwise imported. Reliant on importing components and donations.	P&O services are more available than wheelchair services, with departments in three referral hospitals – Lilongwe, Blantyre (QECH) and Mzuzu.	P&O training is accessed outside of the country at TATCOT.	for salaries but does not provide for the operational side of provision of devices (except P&O where they provide something towards operational costs)	Council for the Handicapped (MACOHA) and the subsequent Disability Act (2012) has a section on AT, also one on empowering disabled people and provision of AT. Policies are in place; however, implementation is lacking.
4. Spectacles	Donated and imported. Limited availability and high cost.	Available in some private pharmacies or shops. Otherwise available through NGOs. Should be more widely available but no services have been set up to provide spectacles other than through the private sector.	No specific training available.		There are strong DPOs, including the Federation of Disabled Organisations of Malawi (FEDOMA) and Parents of Disabled Children Association of Malawi (PODCAM) which are active in lobbying. The

5. White canes	Reliant on donations.	Some provided through	No specific training		wheelchair taskforce, however,
		MACHOA CBR	available.		is not very active.
		programmes.			
6. Behind ear hearing aids	Imported. Very limited	Montford Special Needs	No specific training		
	availability and high cost.	Education College	available.		
		(Catholic Church			
		Institution) is working in			
		partnership with the			
		Government (the			
		Government provides			
		salaries) and accesses			
		some hearing aids, but			
		otherwise only available			
		through private clinics.			
7. Personal digital	Rare in Malawi, and only ava	ailable to those with the finance	cial capacity to purchase from o	outside the country.	
assistants					

7.4 Table	e 11: Rwand	la deep dive	results
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Rwanda	Products	Services	Training	Finance	Enabling environment
1. Manual wheelchairs	Reliant on donated	No organised, coordinated	A PT and OT course is	Most funding for	Signed and ratified
	wheelchairs from outside	(or trained) wheelchair	available at The University	wheelchairs, walking aids	UNCRPD & optional
	the country (often	services. Some district	of Rwanda. (The	and prostheses is sourced	protocol (2008).
	inappropriate). There is no	authorities provide	Government pays staff	through donations by	
	known local production.	wheelchairs using	salaries and students pay	churches and INGOs.	Signed other relevant
		physiotherapists	fees.)		international and regional
		(untrained in wheelchair		Some funding is available	agreements. (See Sida
		service provision at either	Some training on	for disability at district	2014c).
		WHO Basic or	wheelchairs and walking	level, which can be	
		Intermediate level). Some	aids is included in the PT	leveraged by DPOs for	The MoH is responsible for
		churches, rehabilitation	course.	assistive devices, although	providing health care
		centres and the MoH also		this can be difficult.	services to persons with
		distribute wheelchairs	No WHO training in		disabilities and AT.
		(untrained).	wheelchair provision is	Rwanda has a Basic Health	
		Some rehabilitation	available, at either Basic or	Insurance scheme which	The 2003 Constitution,
		centres can repair	Intermediate level. No	does not currently include	amended in 2010,
		wheelchairs but have	training in repair and	disability or AT, however,	established the National
		limited capacity	maintenance is available.	this is under development.	Council of Persons with
		(untrained).	No user training is		Disabilities (NCPD), an
2. Walking aids	Some wooden crutches	Walking aids are provided	available.	In National Referral	independent public body
	are produced in country by	mainly through		Hospitals salaries are paid	with an advocacy,
	rehabilitation centres.	rehabilitation centres.		for by the government.	implementing and
	Otherwise imported.			Some service providers	monitoring role. The
	Aluminium crutches and			can claim a percentage of	Ministry of Local
	other walking aids			the cost of the device from	Government, Good
	imported through private			the Government, and the	Governance, Community
	businesses – notably			user must pay a	Development and Social
	pharmacies.			percentage (approximately	Affairs is the focal point
3. Prosthetics (lower limb)	All components are	Prosthetics are provided	A P&O Diploma level	10%). Otherwise, the cost	for the NCPD. (Sida
	imported. Production	through rehabilitation	training course is available	deports (INCOs such as	20140).
	takes place in 4/5	centres (either	at the University of	Christoffel Blindonmission	
	centres/nospitals in the	Government or NGO).	Rwanda. Some technicians	(CRM) Humanity &	
	country and quality is 'fair'		are also trained outside	(Colvi), numanity &	
	according to key		the country at IAICOL.		
	informant.				

				Cost is a limiting factor in	
				meeting the demand for	
				products (especially	
				prosthetics and	
				wheelchairs).	
4. Spectacles	All spectacles are	Kabgayi Eye Hospital is the	There is training in	Privately funded and users	
	imported through private	main referral hospital. One	optometry available but	must pay. Not covered by	
	clinics/hospitals.	Sight, an INGO, supports	there are few	insurance schemes so	
		optical workshops in	optometrists.	some NGOs subsidise the	
		different hospitals. Eye		provision of spectacles.	
		services are generally well			
		coordinated through			
		private clinics/hospitals.			
5. White canes	White canes are imported	Available through Kabgay	Some training for users in	Orders for importing white	
	as and when needed and	Hospital, Schools for the	Schools for the Blind	canes are made	
	are not readily or widely	Blind (Rwamagana,	(Rwamagana, Kibeho)	specifically and funded by	
	available in the capacity	Kibeho) and NGOs, but not		NGOs (Light for the World	
	that they should be.	through an organised		and CBM support, One	
		service structure.		Sight. Also support from	
				Fred Hollows Foundation	
				and Vision for a Nation	
				Work in Prevention of	
				Blindness).	
6. Behind ear hearing aids	In general hearing aids are	Some hospitals have ENT	No specialist training for	Any hearing aids available	
	not available. Few are	departments but in	hearing aids.	are funded privately or by	
	distributed by NGOs due	general they are very		NGOs due to the high cost.	
	to the high cost.	poor, with only			
		rudimentary services for			
		hearing aids and no			
		specialists. Any hearing			
		aids which are provided			
		through donors are not			
		maintained (and batteries			
		not replaced).			
7. Personal digital	Have not been seen to be av	vailable. Only available to those	e with the financial capacity to	purchase from outside the	
assistants	country.				

7.5 Table 12: Tanzania deep dive re	results
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Tanzania Products	Services	Training	Finance	Enabling environment
1. Manual wheelchairs Most services will not have	e Key players are the	TATCOT offers advanced	The Tanzanian Health	Signed and ratified
2. Walking aids full range of AT available.	Government (Government	training in P&O, including	Insurance Scheme does	UNCRPD & optional
3. Prosthetics (lower limb) AT that are available do	hospitals) and local NGOs	a 4-year BSc and 3-year	not cover all AT and	protocol (2009).
not meet the scale of	(faith based) which	Diploma level course.	therefore individuals have	
demand.	supplement government	TATCOT also offers a 1-	to pay/access through	Signed other relevant
	service provision.	year Certificate courses in	private insurance (limited)	international & regional
Local production		prosthetics, orthotics and	or donations.	agreements. (See Sida
(wheelchairs and mobility	There are some ongoing	wheelchair technology		2014d)
devices only) has limited	projects providing hearing	respectively.	Funding is not available for	
capacity.	aids and spectacles. There		service provision.	The MoH and Social
4. Spectacles	is significantly more work	No knowledge of specific		Welfare are responsible
5. White canes Imported spectacles and	focusing on service	training available.	Funding for training (P&O	for AT.
6. Behind ear hearing aids white canes are more	provision for visual		and wheelchair) is	
readily available through	impairment than on		available through	The 2015 Constitution
the private sector.	service provision for		government support of	recognises the rights of
	physical impairment,		staff salaries and tuition	disabled people and has
Importation of AT is	including P&O.		fees (including a Student	some provisions for
complicated, and a centra			Loan Board for BSc	disabled people.
supply would help to mee	t In the area of P&O, trained		students), notably tuition	
the need.	professionals are not		fees are paid by	The Disability Act (2010)
	being absorbed into		INGOs/governments for	set up the National
	services; services are not		international students.	Disability Council and
	growing at the rate			provides for healthcare
	expected and are of poor			but is not fully
	quality.			implemented. (Sida
7. Personal digital Have not been seen to be	available.			2014d)
assistants				The Tenneric Dhusiael
				The Tanzania Physical
				Renabilitation Platform
				was set up in 2016/17to
				develop a strategy of AT
				and work on
				and work on
				and work on mainstreaming in

7.6 1	<b>Table</b>	13:	Uganda	deep	dive	results
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Uganda	Products	Services	Training	Finance	Enabling environment
1. Manual wheelchairs	All regional hospitals are	Government regional	The Government has one	The Ugandan National	Signed and ratified
2. Walking aids	expected to produce	hospitals provide services.	training school for P&O,	Minimum Health Care	UNCRPD and optional
3. Prosthetics (lower limb)	devices but there is no		one for PT and one for OT.	Package (UNMHC) under	protocol (2008).
	funding for tools and	There are also some		the Ministry of Health	
	materials.	private rehabilitation	Training goes up to	provides for rehabilitation.	Signed other relevant
		centres (e.g. Katalemwa	Diploma level.		international and regional
	There is a gap between	Cheshire Home)		There is no funding to	agreements. (See Sida
	global technological		Lack of training is a	produce devices in	2014e)
	advancement and		significant obstacle to the	regional Government	
	available technology in the		provision of services.	hospitals.	The Department of
	country for production.				Disability and Elderly
				Some private	under the Ministry of
	Most devices are available			rehabilitation centres (e.g.	Gender, Labour and Social
	through donors importing			Katalemwa Cheshire	Development is
	new products e.g.			Home) produce devices	responsible for AT. (Sida
	wheelchairs are available			but funding is sourced	2014e)
	through NGOs such as			through donors.	
	Motivation, World Vision				The 1995 Constitution
	and Latter-Day Saints				recognises the rights of
	(LDS). Also, there is some				disabled people.
	Importation of second				The Development the Direchiller
	through Determ				Act (2006) and National
	through Rotary.				Act (2006) and National
4. Spectacles	Available in regional beenite	le hut often vie private		-	Policy of Disability in
4. Speciacies	Available in regional nospitals but often via private				implementation of Act)
	clinics attached to nospitals. The private sector is the				provides for healthcare
5 White canes	Indin player.		No knowledge of specific		addressing disabled
6 Behind ear hearing aids	Some are produced locally, but mostly imported.		training available.	The private sector is the	people's rights. (Sida
o. Definite car ficaring alus	a g Enabling Services 1td cells bearing aids			main player. No funding is	2014e)
		is nearing alus.		available.	
7. Personal digital	Have not been seen to be av	ailable.	1		
assistants					

## 8 Appendix 2: Innovation: Scoping exercise in Kenya

#### 8.1 Summary

Initial conversations with colleagues in Kenya, when planning the scoping trip to Nairobi, indicated a strong bias towards scaling manufacturing within Kenya. However, it was clear this idea conflicted with the emerging market shaping analysis, which was clearly showing that global procurement would be necessary to ensure sufficient volume of purchase to make the necessary cut in production costs. Therefore, during the initial scoping visit alternative ideas were discussed with stakeholders. The ideas which were floated emerged from conversations as wheelchair users described how they would like to be able to repair their own wheelchair, or technical experts explained how difficult it was to ensure quality control when producing products locally. These ideas were therefore developed with the stakeholders and iterated until the idea of an innovation hub emerged. The idea has since received support from within the Government of Kenya, the University of Nairobi, and Safaricom.

#### 8.2 Methodology

In Kenya, the initial scoping trip was undertaken in partnership with Motivation Africa and therefore has a clear focus on mobility aids. Colleagues in Nairobi University, who recently completed a research project called 'Bridging the Gap' funded by DFID and led by GDI partners Leonard Cheshire, added context on the poverty gap between disabled and non-disabled people in four African countries (Kenya, Uganda, Sierra Leone, and Tanzania).

Conversations were held with a mixture of stakeholders including disabled people, NGOs, DPOs, Manufacturers, Ministry of Labour and Social Protection, British Council, private sector companies and academics.

#### 8.3 Results and emerging ideas

The details of the ideas which emerged during the scoping trip were developed with partners. The aim of this exercise was to help further develop these so that they can be assessed by local partners and considered as commitments which could be taken forward to the Global Summit.

Our scoping work reflected the importance of AT to people in Kenya. Examples included a young Kenyan child who had cerebral palsy and who had been confined to lying in a bed all day when he had become too heavy for his mother to carry. At the age of seven he received a wheelchair through Motivation and this had allowed: 1) the child to be able to play with his sister; 2) a greater level of engagement with his father 3) his mother's time to be freed to allow her to engage in economic activities and finally, 4) the family to attend church together. In short, it had provided freedom and increased quality of life for the whole family. However, there was still no link to education for the child.

From our Kenya research, we plotted an example of the many interactions necessary to get access to a wheelchair in the emerging diagram shown in **Error! Reference source not found.**. This picture s hows a clear barrier between the main stakeholders such as the Kenyan National Council for Persons with Disabilities (NCPWD), people with disabilities, and the university and entrepreneurial sectors. This is an emerging picture and is meant as a starting point for discussions on how to improve the process and system.





#### 8.4 Second series of consultations, Kenya

#### 8.4.1 Introduction

The GDI Hub sent a small delegation to Kenya between the 21<sup>st</sup> and the 25<sup>th</sup> of May 2018. The aim of the second series of consultations was to support the development of a county-wide consensus on commitments Kenya could take on in terms of assistive technologies as well as to ascertain the AT innovation ecosystem in Kenya, particularly on its ability to host a regional East African innovation hub. The GDI Hub delegation also met with the WHO Country Representative and other high level Kenyan stakeholders.

#### 8.4.2 Methodology

On Wednesday May 23<sup>rd</sup>, 2018, the GDI delegation hosted the Kenya Disability Innovation Stakeholder Workshop in partnership with the Science and Technology Park of the University of Nairobi. The meeting served as a platform to explore the role of innovation and assistive technology on disability inclusion in Kenya and the larger East Africa Region. The meeting was designed to be a space to explore how to take forward innovation for disability for inclusion what type of investment and approach is required if Kenya is to play a lead role in building an East African inclusive innovation/assistive technology ecosystem, as well as an innovation hub in Nairobi. The meeting also focused on what an inclusive innovation ecosystem would look like. The findings of the meeting informed a consensus for the innovation deep dive session during the Kenya Disability Innovation Summit happening at the end of that week. The event was attended by personnel from the Kenyan Ministry of Labour and Social Protection, DFID Kenya, University of Nairobi, local DPOs and other local stakeholders.

On May 24th, 2018, the GDI delegation participated in the Global Disability Pre-Summit event in Nairobi. The Pre-Summit served as a stage to prepare Kenya to participate as co-host to the Global Disability Summit happening during the summer of 2018 in London. The objectives of the Pre-Summit event included developing an analytical country status report to form the basis for gaps identification and subsequent commitments, as well as to develop a consensus on commitments DPOs wanted the country to consider. More than 200 DPOs representatives attended the Pre-Summit as well as

representatives from the Kenyan Government Ministry of Labour and Social Protection, DFID Kenya, and several other INGOs.

#### 8.4.3 Findings

The main elements that emerged from this exercise are aligned with the results produced by the collective exercise conducted by the Kenyan Ministry of Labour and Social Protection during the Global Disability Pre-Summit. AT affordability is one of the themes that appears frequently. Disability and poverty are highly interrelated, so having access to affordable AT is a priority for disabled Kenyans. The second theme is that of training and capacity building. The group expressed a need to ensure that professionals are well trained and that such training can be extended further geographically. Awareness is another theme. In Kenya, there is still a pressing need to raise awareness within the disabled community about AT products and how they could be used. Additional points on the quality of AT, taxation of imported AT, encouragement for disabled people to innovate, and opportunities for inclusive education were also mentioned.

# 9 Appendix 3: Market shaping analysis – wheelchairs and hearing aids

#### 9.1 Summary

Under a largely fragmented, non-integrated, and under-invested AT sector, BCG conducted a USAIDfunded AT market shaping research exercise focused on understanding current market shortcomings and barriers to uptake for two prioritised APL products: wheelchairs and hearing aids. The market shaping exercise also sought to develop systemic recommendations to drive uptake of wheelchairs and hearing aids, as well as to apply lessons learned from wheelchairs and hearing aids to inform recommendations for the broader AT sector. Finally, the exercise was aimed at facilitating coalition building among key stakeholders to enable continued momentum and coordination beyond the exercise.

The exercise engaged a wide range of stakeholders among which were development agencies, international organisations, specialised UN agencies, humanitarian institutions, international financial institutions, disability research centres, non-profit organisations and universities, as well as disability-specific organisations and AT sector industry leaders.

#### 9.2 Methodology

A multidisciplinary methodology was used, that included a literature review, around 60 primary interviews – among which there were 10 bilateral, 10 multilaterals, 35 technical experts, NGO, and academic, as well as 5 private sector interviews – a quantitative and qualitative data assessment to prioritise APL products, and a two-day workshop with more than 30 key stakeholders to align on barriers and prioritise potential interventions.

To address the challenge of unmet AT needs, several key questions were addressed, such as "what are the barriers?" "why are they happening?" "how can we remove the barriers?" "who should be involved?" and "what is the path forward?" The objectives were to determine the barriers to supply and demand for AT, to identify the underlying root causes of key barriers, to develop interventions targeting underlying causes to remove barriers, to identify necessary stakeholders to ensure successful implementation of interventions, and to develop a plan for product or broader AT sector. The BCG framework aimed to address these questions based on an analysis of the supply and demand drivers of AT uptake, identification of barriers and an understanding of the nature of such occurrences (see Figure 12).

Additionally, to understand barriers and possible interventions, country archetypes were developed – among which were included characteristics of AT development such as economic development, disability prevalence rates, political will and commitment, healthcare systems, quality standards, and NGO dependence for the provision of AT. For this exercise, the selected four countries for deeper diagnosis were Malawi, Kenya, the Philippines, and Chile.

To understand the barriers and root cause to uptake, the analysis conducted included an evaluation of the overall global market for both wheelchairs and hearing aids to establish a baseline, which included an overview of the need for selected AT product, service delivery model, supply and policy guidelines, market size and key manufacturers, and product range. Country-specific analyses included a root cause analysis as well as an overview of the disability and AT policies at country level, AT financing mechanisms, AT production and procurement, user service delivery approach and key stakeholders. Barriers and root causes were identified for each country along with common barriers across countries.

## Our framework to address these questions was based on supply & demand



Figure 14 The BCG framework addressed questions based on supply and demand factors.

Finally, the methodology also considered a range of potential interventions in developing recommendations to improve AT uptake. These interventions were divided into four different categories: market shaping, programmatic, policies/guidelines, and advocacy. All four types of interventions highlighted could take place at different levels (e.g. global, national) and would require financing solutions for support. When the workshop participants developed and prioritised potential interventions to address the identified barriers for both wheelchairs and hearing aids, assessment criteria were used that included three factors: the intervention's impact, its feasibility, and organisational priority and interest. Detailed overviews of the prioritised interventions for wheelchairs, hearing aids and the AT sector at large were developed, including the key objective, activities, critical success factors, and lead stakeholders.

#### 9.3 Findings

In terms of wheelchairs, the market shaping exercise found that while there were varying levels of AT market development across countries – ranging from low AT market development (Malawi) to medium (Kenya and Philippines) to a high level of development (Chile), key barriers were common across all countries and could be classified into five main categories related to both demand and supply factors. In terms of demand-caused barriers was *Awareness* (demand), while supply-caused barriers included *R&D* + *Manufacturing*, *Procurement*, *Human Resources*, and *Service Delivery*.



Figure 15: Demand and Supply Barriers in the AT Wheelchair Market, as identified by the MS exercise.

In terms of hearing aids, the market shaping exercise noted that country AT development levels also ranged from low AT development (Malawi), to medium (Kenya and Philippines), to high (Chile) in the same way as discovered in the wheelchair findings. In the same way that the wheelchair markets, hearing aids barriers were found to be grouped under four main categories *Awareness* (demand), *R&D* + *Manufacturing*, *Human Resources*, and *Service Delivery*, the latter responding to supply factors.

#### 9.4 Moving forward

The exercise concluded that, despite initial progress in developing interventions for the wheelchair and hearing aids sectors, the need for AT access and uptake remains significant. Considering this, the stakeholders involved in the project concluded that to effectively address the significant global needs for AT, concerted efforts beyond the individual product-specific recommendations developed for the wheelchair and hearing aid sectors are needed to coordinate and scale available resources. As such, the exercise included specific recommendations for a coordinating platform that can bring together a diverse group of partners to enable catalytic interventions that increase the availability and affordability of AT.

# 10 Appendix 4: Market shaping deep dives – spectacles, prosthetics and orthotics and PDAs

#### 10.1 Summary

CHAI is funded by DFID through the 'Strengthening Health through Affordable Prices and Efficiency (SHAPE)' programme to accelerate access to new and improved health commodities, through both supply and demand-side interventions. The DFID-CHAI partnership works to improve market dynamics by securing price reductions for drugs, diagnostics, and vaccines, addressing gaps in the flow of market information, incentivising the development of products for resource-limited settings, and working closely with country governments to ensure sustainable outcomes with meaningful impact. As part of this ongoing work with DFID, CHAI undertook initial scoping of three specific priority AT: 1) Spectacles, 2) Prosthetics and Orthoses (P&O), and 3) Personal Digital Assistants (PDA). CHAI also worked with data gathered and analysed by BCG on hearing aids to assess market shaping potential. The purpose of these assessments was to outline the factors inhibiting the uptake of several AT in low-resource settings, the implications of these factors when designing initiatives to increase access and suggest initial directions for market shaping.

#### 10.2 Methodology

For this scoping assessment, the primary method used was desk research. CHAI used publicly available data and reports from UN and NGO sources, academic journals, news media, and market reports. This data was used to collate known key issues in the market as well as to generate market size estimates. These findings were then supplemented with expert interviews to better understand key market dynamics that were not immediately evident from the literature, and to understand service delivery in greater depth. Two of the expert interviews were conducted in Malawi to provide real-world context. GDI Hub accompanied CHAI on some of these interviews as well.

Organization	Experts Interviewed	Date			
1) Spectacles					
International Eye Foundation (IEF)	Victoria Sheffield, President and CEO	April 5, 2018			
	John Barrows, VP Programs				
VisionSpring	Elizabeth Gudwin, CEO	April 19, 2018			
EYElliance	Jordan Kassalow, CEO	April 24, 2018			
	Elizabeth Smith, Co-founder				
International Centre for Evidence in	Hannah Kuper, Director	April 26, 2018			
Disability, LSHTM					
Vision for a Nation	Tony Fulton, CEO	April 26, 2018			

Table 1: Expert interviews conducted by CHAI for AT product scoping

Blantyre Institute for Community Ophthalmoloay (Malawi)	Stanley Yohannes, Optometrist	May 1, 2018
2) P&O		
D-Rev	Kathy Donaldson, CEO	April 18, 2018
	Rob Weiss, Product Manager	
	Sarah Tollefson, Director of Impact	
Exceed	Carson Hart, CEO	April 26, 2018
500 Miles Kamuzu Central Hospital	Austin Mazinga, Head	April 30, 2018
(Malawi)		
3) PDA		
UNICEF	Gopal Mitra, Programme Specialist –	April 5, 2018
	Children with Disabilities	

Initial research on PDAs indicated three factors that led to the decision to discontinue analysis on this product category. Specifically: 1) A review of the WHO global survey results found that PDAs were ranked relatively low compared to other products in the second round of the Delphi method; 2) this product is actually a wide variety of products, many of them facing obsolescence as accessible smartphone apps proliferate; and 3) initial understanding of the uptake and market barriers indicated the likelihood of a potential market shaping intervention to be very low.

CHAI therefore pivoted to focus instead on hearing aids and leveraged initial scoping work conducted by BCG for USAID to draw additional conclusions about the potential for market shaping for hearing aids but did not conduct any research that was supplemental to that conducted by BCG.

The findings of the scoping research were reviewed by market shaping experts at CHAI to develop initial recommendations, based on CHAI's experience with market shaping interventions for health commodities in the past. Analysis was conducted per each specific commodity and the commodities reviewed were not grouped together, as the market dynamics of each were unique.

Because these scoping exercises were high level, they were completed on a short timeline and there are some limitations to the analysis. We are reliant on existing market data, which may contain systematic errors or assumptions that we were not able to reflect. The interviews were conducted only with prioritised stakeholders that emerged from early reading and did not include a broad range of academic experts, innovators, or users. As a result, many of the recommendations were limited to identifying areas of additional required analysis to determine specific next steps. At this stage of scoping, CHAI was not able to identify a specific deal opportunity tied to a specific product.

#### 10.3 Findings

In this section, the findings are grouped by AT to draw out specific findings for that AT.

#### 10.3.1 Spectacles

The scoping for spectacles identified a market that is shaped by the following key characteristics:

- High level of need, with a conservative estimate of 1.4 billion people with poor vision that could be corrected by spectacles. Meeting this need has potentially high benefits for health, productivity, and literacy, but even in areas where the need is disproportionately high, this does not necessarily translate into product demand.
- The global eyewear market is led by two suppliers, but most of affordable provision in low resource settings is through NGOs. That said, affordable spectacles are available, but the costs

of provision are largely due to systems costs. Research suggests that most lenses are manufactured in China or India, with finishing for high-cost spectacles elsewhere.

• A number of technologies exist both to simplify vision diagnosis and to accurately provide needed vision correction, but their reach is currently limited.

The following key barriers restrict access to spectacles in low resource settings.

- Low awareness: A high proportion of individuals are either unaware of their vision needs or unaware of treatment options available.
- Low acceptance: Cultural stigmas and misinformation inhibit care seeking, uptake and use of spectacles in low resource settings.
- Limited number of trained professionals: Eye health worker shortages are exacerbated by regulations that inhibit task shifting and require high levels of training for professionals.
- Low accessibility: Most people are not obtaining vision screening regularly and may not be aware that they have vision that could benefit from correction.
- **High service delivery costs**: Vision care costs are system-driven rather than product-driven.
- **High out-of-pocket costs**: In some contexts, prohibitively high costs of service are a barrier to accessing vision care, and the majority of service payment is from private sources.

#### 10.3.2 Prostheses and orthoses

The WHO estimates that 0.5% of the world population requires P&O. This would correspond to 35-40 million. Data on unmet needs for prosthetics and orthotics are lacking in most countries; but only an estimated 5–15% of the people who could benefit from assistive products have access to them, including P&O. In the developing world, trauma (e.g. road accidents), disease, and natural disasters result in hundreds of thousands of amputees a year. An estimated 80% of world's amputees do not have access to modern prosthetics.

The following key points summarize the findings related to P&O.

- Providing quality prosthetic services is an end-to-end process that cannot be 'simplified'. Different steps of the care continuum include: 1) assessment to determine most suitable device for the patient; 2) fabrication/fitting (devices constructed, fitted, aligned, and adjusted to patient specifications); 3) user training (physiotherapy/occupational therapy performed to reduce injury and maximize benefits); and 4) upgrades, repairs, and replacement.
- Work has already begun on quality standards and innovation in service delivery and product design. The WHO has prepared global standards and an implementation manual (2017) to assist countries in delivering these services integrated into the health system. Additionally, models exist in LMICs to effectively 1) find and refer patients; and 2) conduct assessment and fitting in short timeframes. For example: 500 Miles operates with grassroots partner organisations in rural areas to identify individuals that could use P&O. Depending on the complexity of the procedure, prosthetics are usually provided within the day. Some innovations are trying to make the socket-making process more efficient (e.g. 3D printing), but benefits/functionality are not yet demonstrated.
- **Trained personnel are key to delivery.** Services such as product fitting/building should be provided by trained professionals; training short-cuts should be resisted.
- The prosthetics market is concentrated around a handful of manufacturers, with modern products prohibitively priced for LMICs, ranging from US\$10,000 up to US\$35,000.

- ICRC leads P&O supply in low income countries with a low-cost, single axis knee prosthetic, but its subsidised distribution system may distort the market for innovations. ICRC provides P&O in very low resource settings using a proprietary modular limb system (custom socket + single-axes prosthetic knee costing less than US\$20). Various social innovators have already developed more sophisticated, affordable alternatives to the low-cost ICRC product, but innovators have signalled difficulties to scale due to: 1) cost considerations ("Good enough is good enough"); 2) insufficient evidence on health outcomes for new technologies; and 3) reluctance from NGOs to change. A "game-changing opportunity" presents today as generic manufacturers have entered the market following expiration of IP protection for the Ottobock product originally invented in the 1980s.
- Innovative financing models exist that enable P&O care provision to poorer populations. High quality P&O services are always accessible for wealthy individuals, but very rarely for entire populations. Therefore, it could be interesting to explore and endorse mechanisms that finance care for poorer populations. For example: South Africa's 'road accident fund' is capitalised with fuel taxes and pays for P&O services for poor victims.

#### 10.4 Conclusions and directions for market shaping

Drawing from CHAI's analysis described above, and in the case of hearing aids, from the analysis conducted by BCG, the potential directions for market shaping for each AT of interest are summarized below.

#### 10.4.1 Spectacles

- Build landscape of handheld refractive diagnostic technologies; identify evidence gaps and perform cost analysis for priority technologies to identify opportunities for cost savings
- Work with governments to implement cost-effective service delivery models to incorporate new vision diagnostics and pop-in spectacles for provision, and potential for appropriate task shifting
- Work with vision NGOs to define and disseminate best practices on implementing national vision care services
- Determine feasibility of school health delivery platforms (vision, hearing, HPV, de-worming, etc.)

#### 10.4.2 Prostheses and orthoses

- Build landscape of available prosthetics (including generics) to identify suitable candidates for low resource settings, including manufacturers catering to Indian and Chinese markets
- Build landscape of existing low-cost service delivery models, and delivery organisations
- Build landscape of financing mechanisms, including Road Accident Fund
- Cost component analysis on prosthetics to identify opportunities for cost savings in the manufacturing process
- Identify target countries for potential intensive engagement on strategy development and service delivery and provision

#### 10.4.3 Hearing aids

• Build landscape of specific available hearing aid product/models to identify suitable candidates for LMIC, including manufacturers catering to Indian and Chinese markets

- Build landscape of existing evidence-based innovations in hearing assessment and fitting/ adjustment of hearing aids; both technology and service delivery models
- Cost component analysis on hearing aids to identify opportunities for cost-saving in manufacturing process
- Cost build up for provision of hearing aids in low income settings, including through examining not-for-profit delivery model and costs (e.g. Starkey)
- Identify target countries for potential intensive engagement on service delivery and provision

# 11 Annex 1: A personal reflection of lessons learnt from the wheelchair sector

#### 11.1 Introduction

Without a wheelchair, millions of disabled people in the developing world can't leave their homes, go to school or find employment. Many feel isolated from their friends and family. Many lose their lives to preventable complications. Most live in extreme poverty. It doesn't have to be this way.

Motivation's wheelchairs and services have been creating for 26 years a fairer society where everyone has the freedom to live the life they choose. The case study, as narrated by Richard Frost, co-founder and former CEO of Motivation, recounts the story of the wheelchair revolution and the lessons learnt along the way.

#### 11.2 The origins of the movement

Motivation's first foray into the world of wheelchairs in LMICs came in December 1989 when the three founders (David Constantine, Simon Gue and myself) travelled to Bangladesh and India, to see if the award-winning wheelchair, designed by Simon and David at London's Royal College of Art, was of any value outside of a design studio.

Our first port of call was the Centre for the Rehabilitation of the Paralysed (CRP), which was set up by ex-VSO volunteer physiotherapist Valerie Taylor. The aim of CRP was to provide comprehensive rehabilitation for people suffering a spinal cord injury (SCI). The centre was struggling with all activities and was desperate to get wheelchairs suited to the needs of those with a SCI. Appropriate wheelchairs were not available on the local market, so CRP had already decided to set up its own small production workshop to make wheelchairs. However, the team at CRP, although competent engineers, had no design experience and were totally unaware of wheelchair design and development around the world.

On arriving at CRP, we discussed our design with the team and they asked if we could make one for them. We set to the task and within a week had combined with the local CRP team and built the first Motivation wheelchair. The chair was tested out, the feedback was very positive, and Valerie asked us if we would consider coming back to CRP for a few months to help them start making this new design of wheelchair. We immediately agreed – that was the moment when Motivation was born.

We continued our trip through India and visited several other centres we thought might have the same needs as CRP. Nowhere presented us with the same opportunity to work with such a committed and knowledgeable local partner organisation. Whilst in India we met a representative of ALIMCO, which is the Indian's government's national wheelchair provider. We were staggered at the poor quality of the ALIMCO wheelchairs we saw, but even more by the attitude of the chief engineer who had no concept whatsoever about catering for the needs of the users in their wheelchair design and production.

On returning to the UK we made plans to return to CRP at a later date. Two significant meetings made that happen. Firstly, we were introduced to Ralf Hotchkiss, founder of the Whirlwind Wheelchairs International (WWI) in San Francisco. We also made some valuable contacts at the Rehabilitation Institute of Chicago (RIC).

In the late 1980s and early 1990s, Ralf Hotchkiss was one of the only people trying to set up a systemised production of low-cost appropriate wheelchairs. Most of Ralf's work was in Central & South America and some in East Africa. Ralf, a wheelchair user himself, was inspirational to us all and greatly encouraged us to continue with our project plans for Bangladesh. Ralf made the link to RIC and through that we managed to raise enough funds to start our first project at CRP.

#### 11.2.1 The first lessons

The Bangladesh project taught us many things. We lived and worked in the grounds of CRP and got to know the wheelchair users very well, along with their needs, problems and general obstacles in life. We soon learnt that you can have the best wheelchair in the world, but if you are not healthy enough to sit it in, it can be as good as useless. From that point on our work started to embrace not only product design, but service delivery, training, user needs and engagement, and, fundamentally the desirable aim of sustainability. From these lessons, the Motivation methodology was nurtured.

The Bangladesh project was a success and the workshop is still making wheelchairs all these years later. However, the door to the realities of the sector were only just opening up. Once we had completed work at CRP we were asked to go and work in Poland and then Cambodia. On visiting both places, we realised that the need for the kind of project we had set up in CRP was massive, and global. Bad wheelchairs were everywhere, and nobody was really making much of an effort to make high quality but low-cost wheelchairs. The sector was low-quality and low impact.

#### 11.3 The birth of Motivation

At this point we turned our 'Motivation' project into a registered charitable trust in the UK so we could continue with this work in other countries as they approached us. Working in Cambodia in 1992 we first came across the world of development and met lots of organisation working on the provision of prosthetics for the many thousands of Cambodians who had lost limbs from the indiscriminate laying of landmines. We met organisations such as ICRC and Handicap International (HI – now Humanity and Inclusion) amongst others, and we realised that there was an entire humanitarian aid sector that we were not aware of.

Our natural instinct was to collaborate as much as we could with these large and well-established organisations. Our initial attempts at collaboration were not greatly successful for several reasons. Firstly, nobody had heard of Motivation. Secondly, all agencies engaged in the provision of P&O in Cambodia were struggling to collaborate with each other – there were no standards of best practice for service delivery, financial sustainability or specification for product standards. Finally, we were trying to do something different and innovation/change was not well received.

In Cambodia, we worked hard to establish a reputation – we worked closely with key stakeholders to embed wheelchair services into P&O services to avoid duplications, and therefore unnecessary costs, of setting up siloed wheelchair services. Although this worked in Cambodia (notably with ICRC), it took years before this kind of approach was more widely accepted.

#### 11.4 A collaborative process

Again though, we learnt key lessons which we applied to our work, mainly that collaboration is a natural starting point that should always be explored. From Cambodia onwards, we pursued an open

view of collaboration, and made concerted efforts to engage closely with any other organisation focused on wheelchair provision. At the time this really boiled down to WWI, HI and ICRC. We tried to facilitate an open dialogue and the sharing of ideas and aimed to try and consolidate thoughts on quality characteristics of wheelchair products. Alongside that Motivation started to develop its thinking on wheelchair service models, and a set of training interventions to create professional user centred service delivery.

Over the following years our efforts to collaborate continued but were always constrained by lack of resources and a focus on securing sufficient funds to carry out the field work. As the years went on we were approached by more and more countries to help them set up wheelchair production and service delivery – the need was there but very little demand. In most places we worked, we had to spend as much time thinking about creating financing structures to support the wheelchair services as we did the other elements.

In each location, we started again – designing products and services for a specific context. After the first 10 years we felt like we had established quality models of product, service and training. The base characteristics were being repeated and our thoughts turned to how we could work with the commonalities to try and get more scale. Wheelchairs had to be appropriate and affordable in each location, but perhaps we could look at larger scale, more industrialised production, rather than starting new wheelchair production workshops in each location. We started to see that the important element was not production, but service delivery and training people to run services well.

At this time, we started to explore (with support from private sector business – Kingfisher/B&Q) how we could scale up our production and make flat pack wheelchairs that could be assembled with simple hand tools in any location. We also built up a suite of training tools to make that approach a reality and one that could establish a new wheelchair service in a matter of weeks, rather than the 12-18 months it took at the start of Motivation. With the support of Kingfisher, we found a privately-owned Taiwanese company (Merits Healthcare) based in China to make our new models of wheelchairs.

#### 11.5 Scaling up

Once our thoughts had turned to looking at how we could get some scale in our work (Motivation was at the time working with about 500-1,000 wheelchair users a year, although the global need was in the tens of millions), our focus again turned to collaboration and how we could start to look at quality standards for wheelchairs more globally.

In 2003 Motivation initiated a meeting of three small NGOs focused on wheelchair provision; WWI, Motivation and the Centre for International Rehabilitation (CIR – based in Chicago). We met in Washington DC and agreed to try and create some standards for wheelchairs. At the time USAID was the only institutional donor supporting wheelchair services and products (through the Leahy War Victims Fund), so after our initial meeting we approached USAID (Rob Horvath) to see if they would consider providing some funding for us as a stakeholder group, to work together on creating standards. We suggested that we should try and work with WHO to give any standards global credibility. USAID agreed, we spoke to Chapal Khasnabis at WHO, who also agreed, and we started the process of creating the WHO guidelines on the provision of manual wheelchairs in less resourced settings.

USAID provided funding for the creation of an initial wheelchair working group by adding additional funding to an existing contract with Motivation. Motivation project managed this initial phase of work, presenting an overall plan for standards, developing and slowly building a network of engaged stakeholders.

#### 11.6 A Global Consensus

As a result, in 2006 a Global Consensus Conference on wheelchairs was held in Bangalore, India. Motivation continued to provide the secretariat input, but the conference was jointly sponsored and supported by WHO, USAID and the International Society for Prosthetics & Orthotics (ISPO). It was hosted by Indian NGO Mobility India.

The conference brought together more than 80 stakeholders from around the world and successfully achieved consensus on how to move forward. Two years later, in 2008, the WHO published the wheelchair guidelines, which have been the anchor point for most comprehensive wheelchair programmes ever since.

The essence of the guidelines boiled down to some key issues;

- Wheelchairs need to be appropriate for the user's needs and be affordable.
- Products alone are no good, they must be accompanied with professional service delivery.
- Standards for products and services will achieve greater acceptance if backed by WHO.
- Training for wheelchair professionals was almost non-existent, so had to be created.
- Training efforts need to consider: a task shifting approach; training of grassroots practitioners; training of trainers and training of service managers.
- One size doesn't fit all, and a range of wheelchairs is required to meet users' needs.

The conference and guidelines also clearly illustrated the power of collaboration. If the sector wanted to find scale then it needed to work together, bring in new partners, and engage fully with governments and the private sector. Having guidelines that were globally accepted allowed all these conversations to start. It also helped those involved to address the well-known issues surrounding the mass distribution of cheap wheelchairs and the importation of second-hand used chairs from North America and Western Europe, which typified the 'charity model' embraced by many individuals and organisations trying to address the need for wheelchairs in LMICs.

#### 11.7 WHO guidelines

The publication of the WHO guidelines was a major achievement and step forward for the sector, however the real test was to make the guidelines practical too. Following on from this point, WHO led a process of creating a suite of training courses to enable those wishing to provide comprehensive, WHO-compliant wheelchair services to gain the necessary practical skills and knowledge. A key point of the training was to categorise skill and competence needs into basic and intermediate service levels, and to recognise the need to train managers of services and ultimately to train trainers. Once again, a core group of stakeholders joined the WHO effort to compile, test and roll out the various training modules that were created. Motivation was keen to support the process and made all its existing training materials freely available to the WHO process, and provided input from its clinical and technical staff.

Once the guidelines became established, a range of stakeholders found they could use them as the foundation for further development within the sector. Two key examples are the creation of the International Society of Wheelchair Professionals (ISWP), initiated by USAID and delivered by the University of Pittsburgh to help promote the WHO training and to maintain quality standards in service delivery. Another initiative was the creation of CLASP which is focused on creating a hub model for the supply of a range of wheelchairs, again funded by USAID but run by UCP Wheels.

From a Motivation perspective, one of the most useful applications of the WHO wheelchair guidelines was the work to influence ALIMCO and the government of India to adopt a WHO-compliant approach

to wheelchair provision. At the end of 2016, Motivation signed a license agreement with ALIMCO which will see them produce in large quantities Motivation-designed and WHO-compliant wheelchairs, which will be distributed through services to those from the poorest and most marginalised sectors of the community. Motivation could not have addressed such a significant scale alone, but it was the WHO guidelines that opened the conversations with ALIMCO and Indian officials.

Although the WHO guidelines have radically changed the approach of many in the sector and much work has been done since their introduction on the creation of training packages for service delivery and their roll-out, there is still a long way to go. Scale is still limited, and the sector is still predominantly led by NGOs struggling with limited resources, and awareness of the needs is extremely poor. To achieve the scale that is essential to enable wheelchair users to achieve a lifetime of human potential, nations to meet their obligations under the UNCRPD (which was also launched in 2008); and private sector suppliers need to know what is required, where and at what price. More work needs to be done through even greater collaboration and resource allocation.

#### 11.8 Looking forward

The wheelchair sector may well have come together over several years to create significant change, but the work has only just started. There are many lessons learnt in this journey, many of which can be built on, many of which can be used as a reference point for other AT products and services.

#### 11.9 Lessons learnt

#### 11.9.1 People

- Wheelchair users need to be at the heart of change.
- Wheelchair users have a wider variety of individual needs and as a result need a range of wheelchairs, not just one kind and size.
- Intimate knowledge of users' needs and service model constraints are needed to be successful.
- The need for low-cost affordable wheelchairs is massive, and global.
- Getting an appropriate wheelchair is the just the start of a journey to inclusion and fulfilment for the user, not the result.

#### 11.9.2 Products

- Products should be designed not just engineered, but they must be designed with true insight of, and connection to, users of the product. For example, affordability should be a design consideration.
- Appropriate wheelchairs are not available on the local market.
- Local production is one solution, but it needs to be accompanied with design experience and awareness of wheelchair design and development from around the world.
- Products need to be tested by the users and those involved in the service delivery. Feedback and follow-up are essential for successful design.
- Bad wheelchairs are everywhere, cheap wheelchairs are very easy to make.
- There is a significant market for appropriate and affordable wheelchairs in the aid/development sector. Enterprise approaches can open this demand.
- Platforms for sharing of ideas are vital to encourage innovation.
- The important element is not production, but service delivery and training people to run services well.
- Collaboration with private sector business can be instrumental in developing new approaches.

- Local production rarely produces products of the same quality and low cost as more industrialised production methods.
- CLASP as a hub model for the distribution of appropriate wheelchairs has interesting potential but has so far failed to reach any scale.
- Globally accepted standards for service provision and training need to be matched with standards for products which have the backing of a credible and independent body.
- Industrialised manufacturing approaches need to ensure they do not lose touch with the challenges of local maintenance and repairs, and the availability of spare parts.
- The local production of wheelchairs is often focused on the creation of a small number of jobs rather than the ability to supply the best quality wheelchairs at the most affordable price. Very few local producers can match either the quality or price of wheelchairs made on a more industrial level. This differential increases with volume.

#### 11.9.3 Provision

- National partnerships are key local and knowledgeable.
- The needs of a comprehensive wheelchair service are not widely understood in any country.
- There are many opportunities to integrate AT service delivery into the activities of mainstream development and emergency response agencies.
- Opportunities exist to integrate multi AT service delivery e.g. wheelchair services into P&O services, to avoid duplications, and therefore unnecessary costs, of setting up siloed wheelchair services.
- Local assembly and fitting can create a more bespoke service model, can create more employment, and is more financially sustainable than local production.
- Using the WHO guidelines approach, with appropriate products and training, you can help create new wheelchair services in a matter of weeks, rather than the 12-18 months it originally took Motivation.
- The WHO wheelchair guidelines were key to influencing ALIMCO and the government of India to adopt a WHO compliant approach to wheelchair provision.
- A key element of wheelchair provision is securing sufficient funding to pay for the products and the service. This needs to be addressed from the outset and not left to the end after grant funding for programme delivery has run dry.
- The difference between basic and intermediate level wheelchair services is significant and should not be underestimated.
- Wheelchair services require the input of both clinical and technical staff.

#### 11.9.4 Personnel

- New approaches to service models and training approaches (such as task shifting) take a long time to take hold and require the support of global agencies such as WHO, as well as donors.
- Training interventions are key to create professional user-centred service delivery.
- Training tools are needed for products, services and training this requires training for clinical and technical staff.
- Training efforts need to consider: a task shifting approach, training of grassroots practitioners, and training of trainers and service managers.
- The International Society of Wheelchair Professionals (ISWP) was set up to help promote the
  professionalisation of wheelchair services, to oversee the roll-out of WHO training, and to
  maintain the standards. However, ISWP has failed to make the traction it really needs as it
  does not have name and therefore influence of a body such as WHO. Also, anecdotal evidence

suggests that ISWP is not popular with some stakeholders in the sector who feel it is too academic, under resourced and lacks proximity to and understanding of field level service delivery.

#### 11.9.5 Policy

- Products should be tested against agreed standards and specifications.
- Change and innovation doesn't happen on its own, it needs someone to be creative, to take risks and always requires the input of key people who act.
- Many involved in wheelchair provision do not understand the needs of users, or how to use design to create appropriate and affordable products.
- Seed funding is required to support innovation.
- Nothing will last if the fundamental aim of sustainability is not built into programme interventions.
- There is limited accountability and most in the sector were delivering low-quality and low impact, even when attempting to get some scale. Disability is not often seen as a budgetary priority.
- There were no standards of best practice for service delivery, financial sustainability or specification for product standards, so these needed to be created as a starting point.
- Innovation and/or change is not well supported.
- Collaboration is always a desirable starting point but often individual agencies' culture, survival needs, size, lack of resources, and views on approach make collaboration difficult. Whilst collaboration should be encouraged and explored, it rarely produces the right results if forced.
- More commercial approaches to production/supply/distribution can help scaling up but are not widely embraced.
- Lack of resources generally holds back the scaling up of wheelchairs.
- Quality standards for wheelchairs must have global credibility; in the wheelchair sector this was best achieved through the WHO name.
- Donor agencies can support the long-term sector development through the focused and intelligent use of seed funding.
- A Global Consensus Conference is hard to put together, but the results can be very influential and can stop much of the intra sector disagreement.
- If the sector wants to find scale then it needs to work together, bring in new partners, engage fully with governments and the private sector.
- The publishing of the WHO guidelines illustrated the power of collaboration.
- Setting standards through consensus helped to address issues surrounding the mass distribution of cheap wheelchairs and the importation of second-hand chairs from North America and Western Europe which typified the 'charity model' embraced by many individuals and organisations trying to address the need for wheelchairs in LMICs.
- Supporting nations to meet their obligations under the UNCRPD should be part of the overall narrative.
- Sustainability requires all stakeholders to look creatively at alternative finance models to scale up the procurement of appropriate wheelchairs.
- Government financial support for wheelchair service provision is generally very limited, often badly run and not accessible to those who need it most.
- As much work, if not more, needs doing on creating sustainable finance systems and stimulating demand as any other area.

• Governments react well to the WHO name and the chance to be compliant with WHO guidelines. The WHO name opens doors to high level conversations.

## 12Annex 2: Case studies

The following case studies informed and help shape our thinking.

### 12.1 Case study 1: Creating an inclusive new piece of city – Queen Elizabeth Olympic Park, east London

Formed in April 2012, the London Legacy Development Corporation's purpose is to use the once-in-alifetime opportunity of the London 2012 Games and the creation of Queen Elizabeth Olympic Park to develop a dynamic new heart for east London, creating opportunities for local people and driving innovation and growth in London and the UK.

#### 12.1.1 Summary

London Legacy Development Corporation (LLDC) is responsible for the development of Queen Elizabeth Olympic Park and surrounding area following the 2012 Olympic and Paralympic Games.

One of LLDC's four key corporate 'priority themes' is to "champion equalities and inclusion". This recognises the importance inclusive design had in making 2012 such a success, and in creating better integrated communities.

#### 12.1.2 Problems targeted

The risk was that the fantastic work undertaken to deliver "the most accessible Games ever" was not continued or further built on during the post-Games development of the site.

LLDC recognised that the inclusive design of the Park and venues was one of the key reasons for the success of the Games and ensured that this area of work was championed at the highest level in all post-Games development.

#### 12.1.3 Action taken

LLDC developed a process to help deliver inclusive design across all its development projects as summarised below:

- Senior Inclusive Design Manager LLDC created this specific role to be the key client-side lead on all aspects of accessibility and inclusive design ensuring continuity and consistency
- Inclusive Design Standards LLDC developed their own Inclusive Design Standards (IDS) that all the development on the Park must adhere to, as dictated by planning policy
- Built Environment Access Panel LLDC support an independent Built Environment Access Panel (BEAP) to review all the development work taking place on the Park. BEAP members are made up of disabled and non-disabled people, all with vast experience and knowledge of accessibility and inclusive design in the built environment
- Innovation the Park is constantly changing and LLDC are always looking for ways to innovate and remain at the forefront of accessible and inclusive urban design

#### 12.1.4 Solution, innovation and impact

The result of this work is the creation of an inclusive new piece of city in east London. One example is the 'Timber Lodge and Tumbling Bay Playground', which won the 2014 Civic Trust Award's Selwyn Goldsmith Award for Universal Design.



Some of the inclusive design features include:

- Automatic doors
- Level access throughout
- Good accessible facilities including toilets, Changing Places facility, separate accessible baby change facility, multi-faith prayer room
- Good signage and layout
- Operator (Camden Society's Unity Kitchen) employs over 50% disabled staff
- Playground designed to cater for a broad range of ages and abilities

#### 12.1.5 Next steps

This is a continuous area of work for LLDC that will continue and evolve in line with development work coming forward.

#### 12.2 Case study 2: Prosthetics

### **12.2.1** Provision of high quality, affordable and appropriate upper limb prostheses for adults in Uganda

A 5-day scoping study on the provision of body powered (BP) upper limb prostheses for adults and manufacturing capabilities in Uganda was carried out. Rehabilitation services in Uganda were found to be fragmented, underfunded, under resourced and heavily reliant on donations.

#### 12.2.2 Summary

Demand for upper limb prostheses due to traffic accidents and violence is high in lower and middleincome countries. Provision is poor, highly dependent on donations. Electrically powered prostheses are not suitable for these settings where maintenance is a major challenge, apart from their prohibitively high cost. Local capacity and knowledge needs to be developed to support the sustainable manufacture of prostheses in Uganda.

Research and manufacturing institutions have the motivation and capability of embracing the innovation of upper limb prostheses. Amputees expressed their agreement on the need for affordable and appropriate prostheses, as well as the need for a network for members to share knowledge and foster a community feeling. Researchers from the UK and Uganda will work to innovate an upper limb prosthesis. Its design will be user-centred and its fabrication sustainable. We have given also other recommendations for the solution of problems that are relevant to prostheses in Uganda.

#### 12.2.3 Problems targeted

BP upper limb prostheses for adults are very expensive and difficult to obtain in Uganda. Patients need to travel long distances to the nearest health centre, which also lack resources. 51% of the population live slightly below the international poverty line of 1.25 USD a day.

#### 12.2.4 Action taken

A scoping study on the provision of BP upper limb prostheses for adults and manufacturing capabilities in Uganda was undertaken for a period of 5 days.

This work was performed by representatives from Makerere University, Mulago Hospital, University College London, University of Southampton, University of Salford and the Global Disability Innovation Hub.

Three adults with upper limb amputation talked with the team about their needs, experiences and expectations in relation to BP upper limb prostheses. The team visited centres with known operational capacity to fabricate, assemble and prescribe prostheses.

The scope and funding of their services were explored. The representative of Ugandan manufacturers on all trades and a research institute with known capacity to embrace innovative design projects requiring manufacturing and business skills were also visited.

#### 12.2.5 Organisations visited

- Mulago Hospital
- Mulago Orthopaedic Workshop
- Mulago Hospital Orthopaedic Technology School
- Comprehensive Rehabilitation Services Uganda (CoRSU)
- Katalemwa Cheshire Home for Rehabilitation Services (KCH)
- Orthotech and Physical Rehabilitation International
- Uganda Industrial Research Institute (UIRI)
- Crown Agents Uganda
- Uganda Manufacturers Association (UMA)

## 12.2.6 Findings

- 1. There are no statistics available regarding adults in need of upper limb prostheses.
- 2. Upper limb prostheses are difficult to get, they are not affordable and very often they are not appropriate.
- 3. Existing orthopaedic workshops are highly dependent on cash and prostheses parts donations (including government funded workshops).
- 4. People that need upper limb prostheses are likely to not be able to afford a device from private clinics.
- 5. Prosthetic parts are imported mainly from Ottobock suppliers outside Uganda and other brands from India. All purchases are subjected to taxes on top of their high cost. Other suppliers exist in South Africa, but they are excluded due to their long lead times.
- 6. An Orthopaedic Technologist school trains around 40 technologists per year which struggle to find employment.
- 7. The main reasons adults have limb loss appear to be transport accidents and violence.
- 8. Currently there is no upper limb prosthesis that fulfils the functional needs of Ugandan amputees. Their needs are: wash, carry, hold, pull, wrist rotation, ride a motorbike, cook, eat, use the toilet.

#### 12.2.7 Next steps

- 9. Workshops are highly dependent on donations; support is required to find ways of creating additional sources of income to shift into a sustainable model of operation.
- 10. The International Society for Prosthetics and Orthotics could help improve the standard of upper limb prosthetic provision in the workshops while helping them to achieve certification.
- 11. Uganda has the space, workforce, skills, and motivation to learn and establish the manufacturing of prostheses parts, that are currently imported at a high cost. They require support and guidance.
- 12. Prosthesis users are very likely to be interested in being part of a network to support and inform each other. They require the resources and guidance to establish such a network.
- 13. The establishment of a network of prostheses users will also enable the creation of a national register of prostheses users. This can be used for the collection of demographics and to measure the impact of actions taken to improve the provision of prostheses.
- 14. The execution of any of these recommendation is very likely to benefit also the provision of lower limb prostheses and have a broader impact for children in need of prostheses.
- 15. Modernize copyright to motivate orthopaedic technologists to create innovative prostheses using local resources.
- 16. Restructure taxing to facilitate tax exemption for imported materials and parts used for fabricating prostheses.
- 17. Researchers from UK and Uganda will take a user-centred approach and gather information to be able to develop a high quality, affordable and appropriate body powered upper limb prosthesis that should also be manufactured in a sustainable way in Uganda.

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Figure 16: Mulago Orthopaedic Workshop, Kampala. The workshop is underfunded, over staffed and in need of renovation. Everything in general is worn out and in need of maintenance. There is a table at the furthest point with casts used to produce prostheses. All are for lower limbs.



Figure 17: A BP prosthesis for an amputated arm above the elbow. *This particular prosthesis highlights the situation in Uganda. the arm sections are of dark skin colour while the hand is for a "white person", as the orthopaedic technician's manager explained. This is a prevalent problem in Uganda, where supply of prosthesis parts is limited and matching the skin colour of the prosthesis to the user is impossible. This causes problems such as the patient rejecting the prosthesis.* 

## 12.3 Case study 3: AT for inclusive education

#### 12.3.1 Summary

The United National Partnership on the Rights of People with Disabilities (UNPRPD) is a unique collaborative effort bringing together UN entities, governments, organisations of persons with disabilities, and the broader civil society. The UNPRPD supports the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) by facilitating policy dialogue, coalition-building and capacity development at the country, regional and global levels.

Since 2014, the UNPRPD has been supporting a joint UN programme entitled 'Promoting the Rights of Persons with Disabilities in Uganda' to remove specific barriers to inclusive education for primary school children with disabilities (CWD), particularly those with visual impairments (VI) and hearing impairments (HI). The project seeks to overcome these barriers by building a strong legislative framework, raising awareness and skills around inclusive education; improving accessible core learning materials and promoting the use of AT.

It is one of only 20 or so programmes which are joint investments across many UN agencies on disability.

It is interesting as a case study because it considers how AT can support inclusive education. For GDI, the programme is a very interesting pilot case study because:

- it is genuinely committed multi-agency which combines pilot testing AT interventions with a broad method to generating a comprehensive policy framework for mainstreaming an inclusive approach;
- it moves beyond AT for the individual, considering how AT at a collective level can genuinely influence life outcomes; and
- it is a good demonstration of how leapfrog technology opportunities can and will be beneficial.

#### 12.3.2 Problems targeted

Learners with impairments (particularly HI and VI) in large class sizes in 20 primary schools in Uganda were largely excluded from education due to lack of access to accessible teaching materials.

Phase one ran from October 2014 to December 2016 and was particularly successful in creating an enabling policy environment and in piloting a model for the production, dissemination and use of accessible learning materials and assistive technologies for primary school pupils with visual and hearing impairments. It succeeded in delivering the following outcomes;

- **Conducted a thorough audit** using UNESCO model policy as a tool to identify current progress against Inclusive Information and Communication Technologies in Education;
- Created a Draft Policy Annex on ICT and Education to be embedded within the new Inclusive Education Policy for Uganda;
- Developed Accessible ICT procurement policy and guidelines;
- Formed a Policy Board and Management Committee to create a coordination mechanism for stakeholders from the ICT, disability and education communities;
- Developed strong partnerships;
- Built a monitoring policy tool and resources to support inclusive education;

- Oversaw the conversion of learning **materials** (textbooks) in alternative format and their initial testing;
- **Sensitised/trained** approximately 954 people on the use of accessible learning materials and assistive technology to promote inclusive education;
- **Raised the profile** of inclusive education and inclusive ICT through events, workshops and conferences including the 6<sup>th</sup> Africa Forum 'Beyond 2015', reaching beyond Uganda; and
- **Promoted the Use of 'U report' (which is a citizen feedback mechanism)** for the first time by Association of the Deaf and African Youth with Disabilities Network to identify priorities with 15,919 respondents, and collation of life stories and testimonies.

The project received investment of USD\$349,890 in Phase one.

The challenges were as follows;

- Buy-in from publishers;
- Delays in procurement; and
- Need to focus on policy framework before dissemination and 'testing'.

#### 12.3.3 Action taken

In Phase two (which takes place between January and December 2018) the project has been designed to:

- further consolidate the policy reform and monitoring process put in place during Phase I and promote the ratification of the Marrakesh Treaty;
- further strengthen and improve the pilot initiative on the production and use of accessible learning materials in schools with additional training around the pedagogical use of the accessible learning materials; and
- undertake an evaluation impact assessment to build evidence for scale up of the pilot initiative.

#### 12.3.4 Solution, innovation and impact

- Children learning in the 'inclusive classrooms' report much higher levels of engagement
- Students without impairments also learning to engage with disabled pupils through communication and utilise the tool as a mechanism to learn
- Parents and teachers able to engage more, especially with disabled students
- Stronger policy framework in place
- Strong local partnership including with cross sector agencies
- Raised profile of inclusive education
- Marrakesh Treaty ratified
- Good engagement with publishers and NITA-U (IT agency)

#### 12.3.5 Next steps

Despite the success of the pilot project, there is enormous opportunity to further enhance the possibilities for inclusive education through technology, through:

• Connecting the schools to the internet in the first phase of connectivity (of a World Bank funded project) will enable them to become centres of excellence, on inclusion as well as leading the charge on disability innovation;

- Enabling user-generated content by moving beyond verbatim repetition of the text books into sign or audios is a good example of how 'leap-frogging' technology can hugely benefit developing countries;
- Engaging with parents helping them to use the AT to support their children is also an example of how overcoming stigma and supporting families/communities as well as the disabled people is fundamental;
- Building the pilot into the mainstream development arena of education policies and practice (to be supported through local research) shows how Uganda are really committed to taking Inclusive Education seriously and shows the strength of multi-agency partnerships;
- Sharing the knowledge and learning at a methodological level with the UNPRPD programme is something that needs to happen to ensure the strategic learning and the building of a global methodology on disability innovation.



Figure 18: A selection of images taken by one of the students using an iPhone, capturing things they were excited about.

# 12.4 Case study 4: Teacher-Led distance learning opportunities for out-of-school children with disabilities in Zambia

Pupils with disabilities are usually excluded by most schools in Zambia. Even when they overcome the initial challenges of accessing education, children with disabilities experience extended periods of being in and out of school, with little education.

## 12.4.1 Summary

The idea adapts distance learning methodologies to a younger group of learners and promoting inclusion of hard-to-reach learners in the school environment, through distance education. It also focuses on how teachers and materials can effectively support learners at a distance. It will also explore peer support and engagement, so distance learners will access the wider experience of education, including social integration, enabling students to transition to the regular school system if they choose to.

#### 12.4.2 Problems targeted

On the rare occasions in Zambia that pupils with disabilities are not excluded and have access to education, retention and progression become the most difficult barriers to remove. For girls with disabilities, their schooling experience resembles a revolving door where they experience periods of being in and out of school, with little actual education.

Leonard Cheshire (LC), in collaboration with the Open University (OU) proposed to prototype and test distance learning for out of school children with disabilities. Teachers will also benefit from a wider programme run by the OU (www.tessafrica.net) to support their pedagogical needs. The model of proposed learning with a balance of self-directed and teacher led methodologies is likely to achieve more success with the upper primary group targeted. The use and development of open education resources will promote sustainability beyond the project.

#### 12.4.3 Action Taken

Situation analysis to determine:

- I. Education administrative staff and teacher's perception on the viability of the proposed project
- II. Assess level of connectivity by the children with disability in their homes, school and classrooms
- III. Asses the level of connectivity by teachers in their homes, schools and classrooms
- IV. Preparation of proposed intervention

#### 12.4.4 Solution, innovation and impact

The benefit will primarily be to children with disabilities between 10 and 15 years old in rural and urban areas of Lusaka province who have dropped out of school or have intermittent access to education. Teachers will also benefit as they can use the materials to support in school classes and for students to review content at home.

# 12.5 Case study 5: Innovation: Learning from Mexico, A virtuous cycle of disability innovation by youth with disabilities

#### 12.5.1 Summary

Innovation Hubs are vibrant places. They provide a rich array of creative and technical tools, state-ofthe-art technology and materials, accessible facilities, innovative methodologies, and expert guidance to nurture and escalate new ideas, services, and products. Innovation Hubs can also serve as the catalyst for inclusive disability innovation. The Inclusive Innovation Lab in Monterrey shows us that when people with disabilities are part of the creative process and can design their own solutions, everyone wins.

The Inclusive Innovation Laboratory (IIL) in Monterrey, Mexico is part of a regional initiative launched in 2014 to foster innovation and to empower new generations of young people with disabilities through access to state-of-the-art technology, training, collaborative spaces, specialized curricula, mentorship and financial resources for social and economic ventures.

The ILL operates under the premise that solutions to local challenges must come from within the local communities. In this way, the ILL trains young people with disabilities to innovate and to design their own collaborative solutions.

#### 12.5.2 Problems targeted

Young people with disabilities face enormous attitudinal, physical, and informational barriers. As a result, people with disabilities tend to experience more adverse life outcomes. When it comes to access to innovation the results are no better.

Although there are many innovation hubs around the world, and some of them focus on the development of disability innovation, disabled people are usually excluded from this experience. Mainstream innovation programmes are often not accessible to young disabled people, and as a result, disability innovation often does not actually involve many disabled innovators.

#### 12.5.3 Action taken

The Trust for the Americas, the Organization of American States and CAF – Development Bank of Latin America, saw an opportunity to increase access to innovation spaces for young disabled people. As a result, an Inclusive Innovation Laboratory was launched along with the Universidad Tecnológica Santa Catarina in Monterrey, Mexico.

#### 12.5.4 Solution, innovation and impact

- Setting: Open spaces that foster group thinking and collaboration.
- Purpose: Identify and fund innovators whose disruptive ideas aim to solve local challenges.
- Training approach: Coaching in ideas acceleration, marketing, communications and use of state-of the art technology to spark and pitch innovative projects.
- Methodology: Activities lead by coaches who facilitate group interaction and encourage peer support.
- Profile of participants: Self-taught individuals, risk takers, social innovators and entrepreneurs.
- Brand idea: Solutions to local challenges come within the communities. Innovation is the key.
- Brand message: Innovation and collaboration at the base of the pyramid.

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Figure 19: An overview of the innovation process.



Figure 21: An innovation project is being presented in Mexican Sign Language.



*Figure 21:Students participate in innovation activities at the IIL in Monterrey, Mexico.* 

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