Executive Statement

One billion people worldwide – 15% of the world’s population – live with a disability and one household in four has a disabled family member (WHO 2011). Moreover, these numbers are increasing as improved medical care and technology allows many people to survive trauma or injury; improved perinatal care increases child survival; non-infectious diseases become increasingly common; and as growing numbers live well into old age in both developed and developing countries. However, this global disabled population routinely faces disproportionate rates of poverty, social marginalisation and exclusion throughout the life-cycle from key domains such as education, health, and employment (WHO 2011).

The UN Convention on the Rights of Persons with Disabilities (CRPD) (UN 2008), and regional and national legislation in countries around the world, now guarantee adults and children with disabilities rights to these and many other realms previously denied them. However, new ideas, new approaches and new technological adaptations - particularly low-cost, low-tech adaptations for the 80% of these individuals who live in lower income countries - are required if we are to address the unmet needs and rights of this population.

Given the challenges and barriers currently experienced by disabled people, more innovative thinking is needed to meet many of the existing – and future – global development goals. In particular, an innovative approach is required to effecting changes in attitude and resource allocation, and to ensuring the development of improved theoretical and conceptual frameworks and technological responses to the significant challenges faced by disabled persons the world over.
## Contents

1. Introduction ......................................................................................................................... 3
2. Background and overview .................................................................................................... 4
3. Challenges and opportunities ............................................................................................. 5
4. Barriers ................................................................................................................................ 9

Author Biography .................................................................................................................. 13
1. Introduction

This paper identifies a range of theoretical and applied domains in which innovative work on ideas, interventions and technologies would benefit and enhance the lives of the world’s one billion disabled people. Whilst work is needed worldwide, both the translation of existing innovation and technologies into low-cost, low-tech adaptations and the development of new insights and solutions to the many challenges face by persons with disabilities should be a particular priority in developing countries. These challenges are exacerbated by poverty, violent conflict, accidents, disaster and climate change, but innovative work in these areas rarely includes adults or children with disabilities. ‘Innovation’ for persons with disabilities is often conceptualised narrowly in terms of a better wheelchair or an improved prosthetic device, with very little attention being paid to the major social, economic and cultural adaptations that are needed to ensure the full and equal participation in society of the growing number of adults and children with disabilities. Persons with disabilities have themselves been increasingly vocal about what this participation should look like and how it should come about, resulting in a specific human rights treaty for persons with disabilities – the UN Convention on the Rights of Persons with Disabilities (2008). However, it is still too early to measure the Convention’s success in ensuring full and equal inclusion. Moreover, there is growing recognition that despite the Convention, and associated improved legislation and policies, unless progress and innovation in a range of fields (for example, health, economics, information technology, and governance) are applied and adapted to persons with disabilities, important opportunities to improve the lives of the world’s poorest and most marginalized population will be missed. Breakthroughs to overcome these challenges are needed in any or all of these four interlinked areas:

**Attitudinal:** Research and interventions are needed to understand, challenge and change attitudes towards disability among those who make policy and implement programmes, as well as amongst the general population. Laws, programmes and campaigns aiming to change opinion must be matched by systems to monitor and evaluate outcomes and progress over time.

**Resources:** People with disabilities must have equitable access to all resources devoted to international development efforts, which should be matched by carefully constructed and robust technical training and monitoring and evaluation mechanisms to ensure equity and equality for disabled people as members of their communities and societies.

**Technology:** A range of technological innovations in areas such as health, personal care, transportation, education, information and ICT are all needed. These should take into account both local context as well as needs and rights of persons with disabilities.

**Theoretical:** There is need for more evidence-based data and research on disability in order to improve policy, provision of resources, and interventions. This research will help identify both barriers and ways to remove them and must take into account context and local priorities.

Finally, this paper argues that any research undertaken should clearly include people with a range of impairments, across the life-course, and that an equal amount of work is needed to address issues faced by both disabled women and men.
2. Background and overview

According to the most recent data, the global disability prevalence rate is around 15%, with 80% of persons with disabilities living in developing (lower income) countries (WHO 2011).\(^1\) The World Health Organization recognises disability as a ‘global public health issue, a human rights issue and a development priority’ (WHO 2014).\(^2\) It affects families as well as individuals; both persons with disabilities and their families are more likely to be poor and, because of negative social and cultural attitudes, they often face stigma and discrimination. Even when economic, social and political efforts to address poverty are introduced, persons with disabilities may be left behind compared with the rest of the community, resulting in a ‘disability and development gap’\(^3\).

Over the past decade there has been an increasing focus in international development efforts on disability inclusion. Sustained campaigning on behalf of persons with disabilities and their representative organisations resulted in the UN Convention on the Rights of Persons with Disabilities (CRPD) (UN 2008)\(^4\), now ratified by 139 countries. This has led to an increased focus on disability by governments and the bi- and multilateral organisations that provide much of the overseas development aid to lower income countries.

Several of these governments, individually and in member state organisations, have begun to consider how they include persons with disabilities within their development assistance programmes. These include the UK government’s Department for International Development (DFID).\(^5\) The Australian government was one of the forerunners of disability-inclusive policy, with its 2008 policy document \textit{Development for All: Towards a disability-inclusive Australian aid program 2009-2014}.\(^6\) Many others have followed suit, including governments in low- or middle-income countries such as Uganda and South Africa (Lang and Murangira 2009).\(^7\)

The increased attention to disability rights brought about by the CRPD also resulted in numerous publications, including the \textit{World Report on Disability} (2011), and UNICEF’s \textit{State of the World’s Children Report} (2013).\(^8\) Those delivering humanitarian aid and development programmes, in particular non-government organisations (NGOs), have stepped up efforts to ensure the inclusion of persons with disabilities in their practices and programmes. All of these documents have increased attention to, and hopefully increased the inclusion of, persons with disabilities in policies, programmes and practices. However, to date, there are few indicators to measure their success. There is also recognition that, despite these efforts, persons with disabilities continue to be among the world’s poorest and most marginalised populations and many challenges remain.

---


\(^5\) The UK government Department for International Development (DFID) published an Issues Paper entitled ‘Disability, Poverty and Development’ in 2002. This report was one of the earliest to draw attention to the linkages between disability and poverty, and the consequences of both on the lives of people in low income countries. However, this was not actually translated into policy.

\(^6\) \url{http://aid.dfat.gov.au/Publications/Documents/dev-for-all.pdf}.


3. Challenges and opportunities

The first challenge is the growing global demographic shift that is making disability increasingly common. Universally, populations are living longer, but not necessarily healthier lives, and obesity-related chronic diseases (such as diabetes, coronary heart disease, hypertension) and other non-communicable diseases (such as asthma, chronic obstructive pulmonary disease) are steadily increasing. This is true in low- and middle-income countries. Improvements in neonatal care are resulting in the survival of many babies and children who previously would have died, but who live with complex congenital and neonatal conditions which lead to impairment and disability. Improved medication allows people with HIV/AIDS to live longer, but often with impairments (blindness, mental health, mobility).

Moreover, persons with disabilities may be at higher risk of other health conditions, as evident, for example, in the higher correlation of Down’s syndrome with obesity (WHO 2014). At the same time, they may also experience significant barriers (including financial) to accessing healthcare and, subsequently, experience worse health outcomes (WHO 2014).

Environmental factors including violent conflict, accidents, geo-physical disasters and climate change are also contributing to upward trends in the prevalence of impairments. Work in these areas rarely includes adults or children with disabilities. Conflict and disasters cause and compound not only disabilities, but also the poverty and marginalisation associated with them.

A slow increase in attention being paid to this area is resulting in the development of a range of manuals and guidelines that specifically mainstream disability throughout, up to and including the Sphere Humanitarian Charter and Minimum Standards in Disaster Response. This growing interest is reflected in the specific focus in the recent International Day for Disaster Reduction (2013) on disability and the contributions that persons with disabilities can make to reducing the risk of disasters and building resilient societies and communities. The UN International Strategy for Disaster Reduction seeks to build on this in the post-2015 framework for disaster risk reduction.

Other ongoing work in this area includes that conducted by the Council of Europe, which is in the final stages of developing a report and guidelines on 'Including People with Disabilities in Disaster Preparedness and Response'.

Historically, the needs of people with disabilities have either gone unmet or, in higher income countries, often met by resource intense, high-tech solutions. These range from computer-operated prosthetics and electric wheelchairs to smartphones and specialised educational structures and complex (and expensive) service delivery systems. Most are not transferable to, or affordable by, the majority of disabled people who live in low- and middle-income countries. As it was originally

---


12 http://www.unisdr.org/2013/iddr/.

conceived, much of the earlier work on community-based rehabilitation aimed to address this gap by adapting locally available technologies and resources to meet impairment needs (Helander 1993); however these efforts have not been well evaluated or disseminated. Thus there is a great need to review how existing innovation and advances in technologies – as well as conceptual frameworks – are addressing the needs and rights of disabled individuals and populations, and an even greater need for further innovation in both practical and theoretical domains if the lives of the majority of people with disability worldwide are to be improved.

This largely unexplored area is not only of significance now, given the size and needs of the current population, but promises to be an area of unprecedented growth in future in light of the improvements in medical care, survival and longevity noted above. Other, rarely considered arenas will also be important drivers here. For example, the 139 countries that have ratified the CRPD have implemented – or at least committed to – legislation that provides access to health, education, employment, housing, recreation, as well as social protection schemes that increasingly help to provide basic monetary support to help defray the costs of living with a disability. New government and civil society initiatives are bringing growing numbers of disabled children and adults into the classroom and the workforce. All these programmes will build demand among disabled people, their families and their communities for improved access to services. Educational systems will need to be redesigned; employers and businesses will need to make provisions for new users; transportation systems will need to be adapted, and IT and communications networks revamped.

While ‘innovation’ for persons with disabilities is often conceptualised in terms of better wheelchairs or improved prosthetic devices, very little attention is paid to the major social, economic and cultural adaptations that need to be anticipated for the growing number of persons with disabilities who will participate in the societies in which they live. Persons with disabilities themselves have been increasingly vocal about what this participation should look like, and how it should come about. However, there has been relatively little work on the most effective ways and means of engaging policy makers and professionals with persons with disabilities (and their representative organisations). As such, there is tremendous opportunity for innovation and challenge-led creativity in formulating better expert and practitioner responses to the needs of the large and growing population of disabled persons. At the same time, a key challenge is presented by the need to identify and address the factors that are impeding inclusion of persons with disabilities at international, national and community levels. A second challenge is to better understand the needs of persons with disabilities, how these needs may change over time, and how they are linked to rights. More research is needed to address the current lack of data about disabled adults and children, and about specific extant barriers to equality and equity (WHO 2011). This research must take place across a range of countries and contexts, since understanding of and approaches to disability are culturally constructed and mediated and, therefore, culturally specific: what constitutes impairment in one society may not be recognised as such in another.

This is linked to the third challenge: a lack of financial, human and other resources. Whilst this is a

14 Helander, E. 1993. Prejudice and Dignity: An Introduction to Community Based Rehabilitation, New York: UNDP.
15 See for example the work of Leonard Cheshire Disability International: http://www.lcint.org/.
common concern for many populations in lower income countries, the lack of resources for persons with disabilities takes on an added dimension. Because of traditional beliefs, prejudices and/or lack of knowledge and understanding, the needs and concerns of persons with disabilities are often placed at the end of the list of priorities. All too often, the provision of resources for person with disabilities is still considered a charitable act rather than the fulfilment of their rights, and new human rights legislations should ensure that people with disabilities are no longer arbitrarily refused equal access to the services, support and resources they need. There is also widespread belief that service provision for people with disabilities is inevitably specialist and expensive, which is difficult to justify in light of other pressing development challenges. The result is that people with disabilities continue to lag behind their peers, even when development begins to make inroads in the poorest communities. New theoretical frameworks better linked to findings from fields such as economics, international development and global health must be developed if meaningful advances are to be made.

A series of recent breakthroughs have potential to support the development of innovative solutions to these challenges. For example, the increase in awareness of disability-inclusive policy and legislation has led to recognition of the need to gather more data (WHO 2014), and work is on-going in a number of low-income countries to improve data collection. In Cambodia, for example, the Global Campaign for Education has been carrying out combined assessments of children with disabilities, both to screen for impairments and to monitor school attendance. On an international level, work is being undertaken to integrate disability questions into national censuses and large-scale surveys, although there is still considerable debate about the accuracy and cost-effectiveness of such undertakings (WHO 2014). Advances are also needed in research and theory development to explore ways to sever the links between disability and poverty. Some emerging methodologies are being developed to better understand the interrelationship between poverty and disability (Groce et al 2011, Mitra and Sambamoorthi 2014), but this work is still in its infancy.

Clearly, technological advances have begun to generate improvements among some groups of disabled persons. For example, better assessment and diagnostic procedures to identify impairments and meet specific needs are important across all sectors. Therefore, the need for assessments and diagnoses in resource-poor settings, often far from advanced medical facilities, is another realm in which further innovation is needed. Innovative technology has allowed many persons with mobility impairments to be better connected; the wide availability of mobile phones in lower income countries, for example, is revolutionising communication among Deaf individuals who are sufficiently literate to benefit from text messaging.

These examples notwithstanding, we have only scratched the surface of the innovations that improved information communication technologies (ICT) might have from a disability perspective (UNESCO 2013). However, the pace of change is determined by the technological infrastructure

---

available in countries, and it is important to underscore the fact that if innovative technologies for persons with disabilities are not developed at the same rate, the introduction of technological innovation among the general public may exacerbate existing inequalities, such as those between disabled and non-disabled populations or between persons with disabilities living in urban areas versus those who live in rural locations.

Within the healthcare sector, better maternal, perinatal and child healthcare, nutrition, vaccination coverage, access to medicines and availability of (low cost) orthotics, prosthetics, prosthesis and rehabilitation have all improved the lives of people living in low-income countries. However, as yet we know very little about the long-term impact of these improvements – for instance, the impact on health, quality of life and wellbeing, as well as education and livelihood outcomes.

The education sector is another area ripe for innovation. Again, in higher income countries, a range of technical innovations has been used to improve access to education for children and adults with disabilities – from assessments, teaching materials and methods, through to computer-assisted devices. However, as a recent review has revealed, very little is known about the impact of these innovations on education outcomes for children with disabilities in lower income countries (Bakhshi et al 2012). Innovations including distance learning (UNESCO 2013) have also been used to bring education to children who cannot access schools, but again, more research is needed in this area.

There have, similarly, been technological advances in access and support to the physical environment, assistive devices, sports and recreation, transportation and communication, as well as information that supports livelihoods and social services, including welfare support. Less tangible - but no less important - have been changes in the way social support is organised and delivered in recognition of the current emphasis on independence, autonomy and choice for persons with disabilities. For example, in the UK, personal budgets have been relatively successful in enabling persons with disabilities to decide who provides care and support and when and how they use such support mechanisms. Whilst there is growing awareness in lower income countries of the need for adequate social protection mechanisms for adults and children with disabilities and their families (Gooding and Marriott 2007) there is, as yet, little consensus on the most effective mechanisms for delivery, and very limited research on the cost-effective implementation of these mechanisms, or

19 Bakhshi, P., Kett, M., Oliver, K. (2013) What are the impacts of approaches to increase the accessibility to education for people with a disability across developed and developing countries and what is known about the cost-effectiveness of different approaches? London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.

20 See for example the Global Alliance on Accessible Technologies and Environments (GAATES), which brings together individuals and organizations dedicated to promoting accessibility of electronic and communication technologies and accessibility of the built environment (http://www.gaates.org/001About.shtml).

21 See also UNESCO (2013).


what people with disabilities themselves think of them. There is also a need for innovative solutions to improve monitoring and evaluation mechanisms for these interventions. Are social protection programmes reaching all those that they are supposed to reach? Are there any innovative, low-cost strategies to ensure adequate identification of those eligible for support?

Whilst there has been a general increase in awareness and legislation related to disability, there is little research on the long-term effectiveness of existing innovations. It is of concern that the implementation of many current innovative activities cannot be rolled out beyond pilot projects to achieve an impact on more than a handful of people with disabilities. Also often lacking are baseline data and indicators to demonstrate true inclusion or choice. There are many guidance notes, handbooks and such on ‘how to include’ persons with disabilities in international development and humanitarian initiatives, but it remains challenging to ensure that these are ‘institutionalised’ and integrated into mainstream development efforts, as well as monitored and evaluated for effectiveness.

There is also a need for more ‘joined up’ multiagency work. For example, global health efforts to eradicate neglected tropical diseases (NTDs), which can have long-term disabling consequences, or nutrition programmes, are usually decoupled from the disabling effects these conditions may have. For instance whilst polio has been almost eradicated globally, there remain few provisions for the 20 million people – some still infants – who will continue to live with its disabling ramifications for decades to come.\(^{23}\) Despite the vast amounts of money spent on these programmes, there is very little evidence that children and adults with disabilities are benefiting from them. Nor is there any evidence that the consequences of polio-related impairments are being addressed through other international development efforts – for example access to education or employment.

4. Barriers

There are a number of reasons for the relatively limited progress in this field. These reasons are interlinked and as such should be considered together when designing innovative interventions. They can broadly be summed up as:

- **Attitudes:** longstanding entrenched stigma and negative attitudes towards persons with disabilities means that they often are not considered when thinking about the potential application of new ideas, or when new resources are allocated. Many also mistakenly believe that persons with disabilities are inevitably economically inactive; as such, investing in technological advances is not seen as cost-effective in light of competing development priorities.

- **Limited resources:** both human and financial are of concern. The development of new or revised national and international laws and policies are a first step, but these policies need resourcing, and unless there is strong governance and legal support, ensuring environments are accessible and increasing resource allocation for persons with disabilities does not in and of itself reduce discrimination and exclusion. Technical support and training are also needed to bolster human resource capacities on these issues.

- **Technology**: lack of innovation, technical know-how, resources and in some cases, lack of basic requirements (such as electricity, water and sanitation), limits the options for innovation and change in lower income countries.

- **Theoretical/conceptual frameworks**: the lack of evidence-based research has been hampered by conceptual frameworks that do not always fit lower income countries or different socio-cultural contexts.

The breakthroughs needed could come in any or all of these categories. However, as noted above, breakthroughs are only likely to occur if all areas are addressed:

**Attitudinal**: Research and interventions are needed to change attitudes towards disability among those who make policy, those who implement programmes and among the general public. Laws, programmes and campaigns aiming to change opinion must be matched by systems to monitor and evaluate outcomes and progress over time. More innovative strategies are required to produce attitudinal - and subsequently behavioural - change. Some of the most successful strategies have used a range of media to communicate the message about mainstreaming disability (e.g. use of comics, radio, and Facebook to engage youth with disabilities in agricultural activities in Kenya).

**Resources**: People with disabilities must have equitable access to all resources devoted to international development efforts. Access to all resources (human, social and economic) must be matched by carefully constructed and robust technical training, as well as monitoring and evaluation mechanisms to ensure equity and equality for disabled people as members of their communities and societies over time.

**Technology**: A range of technological innovations are required in areas such as health, personal care, transportation, education, information and ICT. For example, whilst there have been enormous advances in high-tech assistive devices, few of these innovations have been translated into low-cost, low-tech adaptations. In addition to providing assistive technology and devices, training on use and maintenance of innovative assistive devices should also be provided locally – this may include providing new areas of employment by training of persons with disabilities themselves on how maintain such devices.

**Theoretical**: There is need for more evidence-based data and research on disability in order to improve policy, provision of resources, and interventions. This research will help identify the barriers, as well as ways to remove them. This work needs to take into account context and local priorities. For example, there has been little critical thinking about the links between disability and poverty – an important avenue for future research. Such research would need to develop econometric models to support the analysis of the dynamics and causalities that exist between disability and poverty in order to identify causal links. Addressing these causal links would help shape policy and focus limited resources – a key focus of development interventions.

The *World Report on Disability* concluded by noting that research on disability crosses disciplines and

---


26 Such as 'Drivers 4 change' in Ghana, who implemented a locally appropriate system of maintenance of ambulances.
countries, and this requires investment in human and technical capacity, as well as partnerships and collaborations (WHO 2011: 267-268). They identified the following key research areas:

- the impact of environmental factors (policies, physical environment, attitudes) on disability and how to measure these impacts;
- the quality of life and wellbeing of people with disabilities;
- barriers to mainstream and specific services, and what works in overcoming them in different contexts;
- accessibility and universal design programmes appropriate for low-income settings27;
- the interactions among environmental factors, health conditions, and disability – and between disability and poverty;
- the cost of disability and the cost-effectiveness of spending on disability programmes.

The significance attached by the WHO to the need to strengthen data collection and support research on these areas is such that they have highlighted it as a specific objective in the proposed WHO Global Disability Action Plan (2014-2021). Finally, it is worth highlighting that there is a need for a longitudinal approach to research on disability, following life-course changes and cohorts for long durations to observe impacts and changes.

Parameters

The first parameter should be an emphasis on research led by, or conducted in collaboration with, persons with disabilities themselves and embedded into mainstream systems when possible. Precedents for this approach include work funded by the UK DFID.28 The research should also be of relevance to the local context and, where appropriate, examples of best practice should be identified, evaluated and widely disseminated. Research should facilitate the transfer and adaptation of ideas which have been successful in one region or context to others – but with the knowledge that one size does not ‘fit all’. There is a need to explore areas in specific sectors (e.g. health, education, livelihoods, social protection, and environment) but also to identify and learn from the links across sectors. The research, and the solutions identified, should be sustainable and build capacity.

More research is needed which explores the factors that perpetuate the exclusion of disabled people from development and innovation, for example, research with community leaders and civil society organisations to sow seeds of change in mainstream communities and structures. This could also include research to analyse and rethink established interventions – attempting to do something new and not just apply established approaches that have worked elsewhere.

27 Universal Design “calls for the design or creation of the environment, products, applications, and content so they are usable by everyone - including people with disabilities - without need for special modification. Universal design is not a one-size-fits-all paradigm; instead it focuses on meeting the needs of each user.” (UNESCO 2012: 76)

28 See for example the work done under the Knowledge and Research stream (http://r4d.dfid.gov.uk/Output/173652/Default.aspx), and the Cross-Cutting Disability Research Programme (http://r4d.dfid.gov.uk/Output/194005/Default.aspx).
Finally, any research undertaken should include people with a range of disabilities; in other words, rather than focusing only on physical disability, it should also include those with cognitive, communication, sensory, mental health and behavioural difficulties. It should address issues across the life-course, and between genders. Some work should specifically focus on disabled children as well as disabled adolescents and their families to explore how a lifelong cycle of exclusion and lack of participation could be prevented in the early years.
Author Biography

Dr Maria Kett, Assistant Director, Leonard Cheshire Disability and Inclusive Improvement Centre, UCL

Dr Kett leads the research team at the centre in planning, implementing and monitoring research projects in the field of disability and international development, particularly in disaster and conflict-affected countries. Where possible, these projects are undertaken in conjunction with Leonard Cheshire Disability International. Current projects include assessing access to education in Sierra Leone and Southern Sudan.

Dr Kett has a particular interest in disability-related issues in situations of disasters and conflicts. Her other main research interests include social exclusion; psychosocial impacts of conflict; effects of displacement, measures to alleviate poverty, and broader issues around development and human rights.

She has undertaken work in countries including Bosnia, Azerbaijan, Sierra Leone, Sudan, Sri Lanka, Pakistan and Liberia. Some of this work includes: 1) Examining the effects of conflict and displacement on the lives of persons with disabilities, 2) Initiating the work of the Crosscutting Disability Research Programme which is establishing a research network across a number of other DFID-funded research programme consortiums; 3) Supporting the capacity building and training of disabled people to participate in research; 4) Undertaking research-based consultancies in collaboration with other international agencies, including the United Nations.

Dr Kett has a strong focus on research in conflict and disaster-affected countries, and has undertaken policy-focused work on inclusive humanitarian responses, culminating in her role as Global Focal Point for Disability in the current revision of the Sphere Handbook on Minimum Standards in Disaster Response (2010).

Dr Kett has extensive experience of working at the interface of research into policy and practice, and was previously the Chair of the International Disability and Development Consortium Task Group on Conflict and Emergencies, and in this capacity represented IDDC to a number of major international donors and organisations, including the European Union and the United Nations. She is also Editorial Representative on the Conflict and Catastrophe Forum at the Royal Society of Medicine.

She is the co-editor of the journal Medicine, Conflict and Survival.