Disability in Low and Middle Income Countries - what it is, and how to change it

Introduction

In this document we summarize how we are thinking about disability and about evaluations in the PENDA team.

This document will be reviewed by our advisory teams. The advisory structure for PENDA offers a broad, critical feedback and input into our scientific framework and approach. We have feedback from three sources:

1. The *Steering Committee* will be made up of representatives of the various high-level institutions involved in *PENDA*. The Committee members will test the usefulness of the knowledge that our approach hopes to develop, especially for future policy decisions in new settings.
2. The *Community Advisory Board* will be made up of disabled academics, activists, writers, leaders, and community representatives. The Board is expected to provide feedback on our overall framework and advice on what learning would be most useful.
3. The *Trial Methods Advisory Group* will made up of five LSHTM-based academics, representing expertise in statistics, evaluations, qualitative methods, economic methods, and disability research. This Group will primarily advise on the design of the individual studies as well as the overall programme of research.

We will share our thinking – imperfect and incomplete – early-on on our website through blogs and webinars. We have also called upon experts– for example, Professor Jo Wolff (political theory) and Professor Chris Bonnell (realist evaluation) – to offer advice. We want to be open to everyone and we will welcome feedback.

Part 1
Disability; what is it?

All people require certain fundamentals in order to live a good life. These building blocks include a good quality education, access to healthcare, ability to work and earn money, plus social networks which provide respect and support, together with control of your own life.

People with disabilities are an extremely varied group, including people with different impairment types, age, gender, ethnicities and living situations. All of these will impact on the experience of exclusion. Disability was once thought of entirely through a medical lens. Disability scholars and activists convincingly argued that it was not the impairment alone that made some people's lives more difficult, but that society was often arranged in ways that excluded them. A clear example of this is for people with mobility impairments: wheel chairs can be as good or even better than legs for getting around, but only if society has chosen to make surfaces smooth and ramps universal. This approach has been refined recently to highlight how disability is not only arising from the choices made by society but from the *interaction* between impairment, psychological factors, society, and the wider world. Many people with disabilities require additional specialist services in order to address their particular needs and thus participate (e.g. rehabilitation, assistive devices, specialist education). Even with these services, some people with disabilities will not be able to participate on the same basis as others, due to disadvantages arising from impairment or illness.

Most people with disabilities are more likely than others not to have access to one or more of the fundamental social goods: their disadvantages **cluster**. These deprivations may occur if they cannot access mainstream

services (e.g. local schools, healthcare facilities), due to institutional and physical barriers and negative attitudes, together with failures to meet their specific needs. Because disability is multi-dimensional, interventions to improve the lives of disabled people may operate at different levels – from the basic level of health, through psychological well-being and attitudes, to environments (social and physical), to the level of law, policy and rights. Appropriate interventions may be different for different people in different settings.

The PENDA project hopes to learn about how to improve inclusion and participation for disabled people in low- and middle-income countries. We define **inclusion** as having equal access to development and health programmes that equally address people's needs. **Exclusion** arises when people have less access. We define **participation** as being able to engage in society in full accordance with one's **capabilities**. The latter notion of 'capabilities' comes from Amartya Sen's work, and refers to the opportunities that people have for achieving activities -- 'functionings', in Sen's language – which they value. The PENDA consortium will seek to evaluate which interventions are effective at maximizing functionings and promoting participation of which groups of people with disabilities. A series of complementary interventions will be selected to test the theory described above.
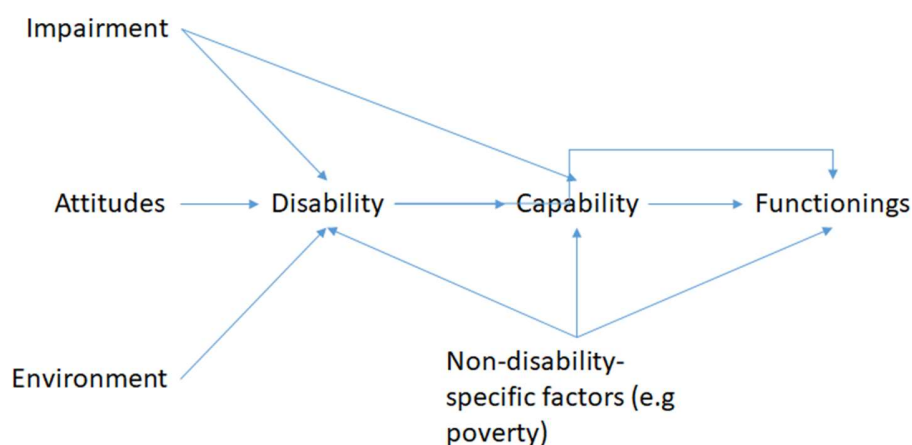
Access to mainstream interventions, plus specialist services in some cases, are usually needed for people with disabilities to enable them to live a good life, particularly in the areas of healthcare, education, livelihood and attitudes. It is anticipated that interventions will work by improving:

1) environment, infrastructure, and institutional capacity to include people with disabilities;

 2) capital of people with disabilities to enable them to participate (for example, financial capital to meet extra costs associated with disability, or human capital such as training);

 3) attitudes towards people with disabilities to reduce societal barriers.

This division is a bit artificial, because in practice, all three mechanisms will interconnect. We assume that interventions will be specific to the intersection of impairments and broad age groupings, and often also work differently according to gender.

Building a conceptual framework

What do we mean by a conceptual framework? Terms such as 'theory of change' or 'theory' are similar in meaning, but unfortunately also have various usages. Our attempt at a draft framework below organizes concepts which we believe come from causal processes relating to disability and capability:

Part 2

Evaluations; what are they for?

Every evaluation involves lots of people: policy-makers, intervention-delivery organizations, evaluators, and communities. Each group may prioritize answering different questions, of which there are at least three types: 'course correction', 'accounting', and 'learning for next time'.

'Course correction' means using the evaluation to alter the intervention in real time by adding resources, expertise and external impartiality to the usual Monitoring & Evaluation practices.

'Accounting' questions try to make an account of the intervention, estimating the bang-for-the-buck and holding the intervention to account (including negative effects). Question about 'impact', 'effect', or 'what works?', are examples of accounting questions. There is a tension between these two types of questions because when the evaluation corrects the intervention is becomes *part of the intervention.* As a result, the evaluation, and evaluators, may be less well placed to make an account of the intervention. In practice, balance is found between feedback from the evaluation in real time and making a formal account of impact.

'Learning for next time' is almost always difficult. It can rarely be assumed that what happened once will happen again in the future. For example, the acceptability of an intervention may vary; some interventions may be sustainable in some contexts but not others; the onward effects of interventions may be different in different places (including the effects on the ultimate outcomes of interest); some interventions may have negative side-effects in some contexts and not others, and so on.

While the first two types of questions are either short-term (course correction), or essentially backwards-looking (accounting), the third type is about drawing-out tendencies and mechanisms, and to contribute to a body of theoretical knowledge (e.g. about design, delivery, and content of future interventions) so that future interventions will be better designed. While building this knowledge may require adequate answers to the first two questions, there may be cases where learning about what to do next time requires different focus.

The three types of questions are answered in different ways.

Course correction is better served by process evaluation, i.e. a detailed analysis of the implementation, mechanisms, and context into which the intervention is delivered. Process evaluations can use quantitative data on delivery, reach, and fidelity to identify bottlenecks, and qualitative data to understand the appropriateness of the intervention and gather open-ended reflections on how the intervention could be improved from a range of perspectives. While process evaluations do seem to explore mechanisms, this is only in the form of what participants think is going on. Process evaluations may report on aspects of the context that interacted positively or negatively with the intervention delivery, and aspects that could have been better used.

Process evaluations are less good at accounting, which is usually the purpose of 'impact evaluations.' The archetypical impact evaluation design is the cluster randomized trial (CRT) comparing the intervention with whatever would normally be available (sometimes referred to as 'business as usual' or 'usual care'). There are designs that do not involve randomization that use statistics to try and get at unbiased estimates of the impact of the intervention. Often an economic evaluation of the costs of the intervention will give a cost-benefit estimate of the outcomes changed for dollar spent.

Alone, process and impact evaluations are not ideal for learning for next time. Many methods have been recommended, although there is no agreement on how to do it best. Understanding different situations may help identify the role that context plays. Varying the intervention may offer insights into how the intervention interacts with context. Testing theories about how the intervention works may help increase knowledge for future intervention development. To satisfy these questions, the evaluation design may need to change. Striking

this balance – learning as much as possible from our evaluations – is a problem that we aim to address through careful preparation, guidance, and thoughtful design across all 10 studies.

Implementation partners, and local stakeholders, will be most impressed by answers to questions about course correction; they will be less interested in being held to account, which DFID will particularly want to see. The default approach may relegate 'learning for next time' to an afterthought.. However, this is unsatisfying from a scientific point of view, and arguably a little short-sighted, since implementers and policy makers look for this kind of knowledge to draw on.

Part 3:

A way forward

PENDA should build and test scientific theory about disability, inclusion, and the design and delivery of interventions. We will need to balance the scientific enterprise against our commitments to the other motives for quality evaluation, in particular: course correcting the interventions in place, and holding the interventions to account.

We have done some thinking about the available interventions to improve the lives of people with disabilities in low and middle-income countries.

1. There are few things that we know can help people and can specify under which circumstances
2. There are some things we know can help people, but we know little about where, why, and how
3. There are many things we suspect can help people, but we have little evidence
4. Intervention effects depend on circumstances
5. Effects over longer causal chains require stronger contextual alignment than short chains

These assumptions imply that for interventions we know work and under which circumstances, such as hearing-aids for people with hearing loss, the focus should move to learning about ways to bring about those circumstances.

For interventions we know have worked, but we do not understand the effect of context, we should be investigating how, when, and why the intervention affects positive change.

For interventions we are unsure will work at all we should try to create the conditions we think will be most supportive.

The importance of context implies that the design of interventions should not be excluded from our research. The design process can involve many kinds of activities, such as searching the literature or doing formative research. Understanding the effects of these design choices should also address where, why, and how the design processes did or did not lead to desired outcomes.