How can we promote the inclusion of people with disabilities in programme design?

The question and the problem

People with disabilities make up approximately 15% of the world's population. Many people with disabilities live in low- and middle- income countries (LMIC), are more likely to experience social exclusion, and socio-economic challenges like poverty, poor healthcare, and social welfare. Yet, people with disabilities are still routinely neglected from the planning and design of international development interventions that seek to improve the lives of people in challenging socio-economic environments. The adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) Article 32 promotes the rights of people with disabilities to be included in all development policies and programmes. In order to fully encapsulate the principles of 'Nothing About Us without Us' within development efforts, a strong knowledge base from programmes worldwide is needed to identify effective ways to promote the meaningful inclusion of people with disabilities in the design and delivery of programmes.

Recommendations

- Recommendation #1: Encourage participation by building in improved systems for disability access

- Recommendation #2: Seek engagement with a wider and more representative range of people with disabilities

- Recommendation #3: Strengthen mechanisms to better evaluate disability-inclusion in programme design

- Recommendation #4: Develop and make accessible opportunities for people with disabilities to gain leadership, research and programmatic skills

- Recommendation #5: Create, adopt and maintain a collaborative ethos for programming that genuinely adopts the principle of equal partnership

"Choice and control is also meaningless if there is no trust in the voice of people with a disability"

Smith-Merry, J. 2019

Challenges

Challenge #1: Attitudinal barriers remain one of the primary challenges for the inclusion and participation of people with disabilities within development programming

- Stigma and discrimination around the assumed competency or capacity of people with disabilities to contribute meaningfully towards design of a programme continues to act as a barrier for inclusion. These beliefs can be damaging and discourage the ethos of equal partnership or co-production within programme design and delivery.

- Long held and damaging belief systems can take a while to change. Even among programmes that incorporate disability-inclusion awareness campaigns, programme staff are found to continually fall back on the bio-medical perspective. They are unaware of social-model concepts that lead them to view people as disabilities as a separate group in need of specialist care who cannot be consulted as equal stakeholders in the project.

Challenge #2: Little consideration for disability access during consultation and advisory activities

- Many programmes still pay little attention to making sure their activities and efforts are as accessible as possible to people with disabilities. There is little benefit to seeking input from people with disabilities if venues are not accessible by local transport links, to wheelchair users or if organisers do not provide sign-language interpreters and visually accessible versions of project material for groups with different needs.

- Another commonly quoted barrier for disability-inclusion work in LMIC development programmes is the perceived cost of integrating this work across different focal areas. Programme staff in low-resource settings particularly feel unable to cover these additional costs given competing priorities and constrained resources

Challenge #3: People with disabilities have often been neglected from interventions that seek to improve their own health, social welfare and opportunities for livelihood

- A majority of disability programming, research and discourse is still controlled by people who do not have a disability and are not representative of people with disabilities' lived experiences and unique knowledge.

- A history of poor practices by researchers and practitioners who have not respectfully engaged with people with a disability has created a lack of trust among potential participants. Power held by specialists can be especially damaging to the process of inclusion e.g. medical professionals hold great power and influence over disability work and can cause disability-inclusion work to become focussed on outputs like rehabilitation even if that's not what people with disabilities identify as a need.

Challenge #4: Lack of evaluation for the effectiveness of disability inclusive development programmes

- There is a significant dearth in the availability of tools that encompass the International Classification of Functioning, Disability and Health (ICF) domains, nor do they have the capacity to effectively measure the effectiveness of disability-inclusive activities and programmes. This gap is especially visible when it comes to the evaluation of participatory or co-production approaches in the design stage of programmes and how these ultimately impact programme outcomes.

- In one review, only 67% of the projects provided any information on the evaluation of their participatory projects. Without proper instruments to measure the effectiveness of disability inclusive activities, aspects related to design, implementation and evaluation will suffer from lack of evidence regarding their level of inclusion and associated barriers and enablers.

Challenge #5: Lack of evidence around barriers and enablers of disability-inclusive work across a diverse range of people with disabilities

- Many developmental programmes still think in homogenous terms about people with disabilities even through this group covers a wide range of groups with physical, sensory, psycho-social and intellectual needs. Projects often prefer to engage groups that they have easy access to, neglecting input from isolated and marginalised communities such as women, children and communities living in rural settings.

How did we find answers

We conducted a review of reviews, examining systematic, narrative, and other types of review evidence on the topic of facilitators to participation of people with disabilities in developmental programming. A search strategy was developed and run in Global Health, PsychInfo, PubMed, Cochraine databases as well as Google Scholar searches. Very little literature was found based on programming solely in low- and middle-income countries, This evidence note is based on the findings of 1 review of low- and middle-income country evidence, 2 reviews which covered literature from a range of settings, and 3 reviews concerning evidence from high-income countries. 3 peer-reviewed articles were also included on the topic that synthesised evidence from 2 high-income settings and 1 from a range of settings.

Evidence-informed Recommendations and Actions

Key Recommendations	Actions
Build better systems of disability access to facilitate ease of participation and inclusion	*Programmes must ensure that all activities being conducted with people with disabilities are accessible according to their needs e.g., meeting times and invitations sent well ahead so that necessary accommodations can be made, seminar rooms and halls have wheelchair access; close to transport links; sign language interpreters or guides are recruited; material and documentation is printed in large print or Braille and have easy read summaries. These considerations should be reviewed by an advisory group of people with disabilities and be revisited and revised continually to reflect any changing or additional needs identified.*
Efforts for engagement need to target a wider range of people with disabilities	*In order to be truly inclusive, programmes seeking input on design should recruit a diverse range of community members, researchers and advocates with disabilities (particularly those that are marginalised) so as to co-create knowledge and learning that is representative to the wider population of people with disabilities. Moreover, co-produced knowledge can support other developmental actors and policy makers in mainstreaming more effective disability-inclusive processes in their programmes.*
Invest in and develop rigorous evaluation mechanisms for measuring disability-inclusion in development work	*An accurate measure of disability prevalence, quality of life and the assessment of impact, barriers and facilitators of participation and inclusion of people with disabilities is crucial to the design of effective disability inclusive strategies and activities. Tools need to be able to able to show if change occurs, measure relevant and important components of inclusion and participation and be sensitive to detect change within the programme's cycle.*
Capacity-building initiatives for people with disabilities to participate in project design	*Involving participants as consultants is a start for a disability-inclusive processes. But to build truly equal partnerships, programmes should invest in time and training to ensure that people with disabilities have the skills and knowledge to engage in design, analytical input and interpreting data so that the process includes the participants concerns and unique interpretations. These needs should be identified through a formal advisory group and consultation process.*
Developing a collaborative framework and ethos for disability inclusive programming	*In order for programming to be truly inclusive, reform is needed within the ethos and framework of this work that guides the provision of support structures (e.g. mentors for community members), establishing a formal advisory board, building trusting relationships and leadership skills, as well as the openness and flexibility of researchers, program managers and project staff to be led by people with disabilities as experts of their lived experience.*

Policy priorities

Supporting the meaningful inclusion and participation of people with disabilities is crucial for developing more equitable and sustainable societies and economies. To achieve this, governments and policy makers need to strengthen systems of accessibility and mainstream inclusive collaboration with people with disabilities, DPOs, disability-rights activists and affiliated stakeholders in national decision-making forums. There is a need for public investment in evaluating inclusive programme design and evaluation to generate evidence for informing appropriate legislative and policy design and highlight gaps for further investigation.

Conclusion

Evidence suggests that societies, health systems and economies benefit from the principles of equal partnership and ownership of programming within disability inclusive development. To make this happen, programmes need to create and sustain practices and ethos that counteract traditional power imbalances, adopt more inclusive policies, language and address the diverse needs of people with disabilities required for participation. Development programmes need to move beyond passive consultations and seek meaningful engagement from people with disabilities from the early stages of programming right till the end so that the solutions and lessons learned are inclusive and representative for people with disabilities worldwide.

GAPS & RESEARCH NEEDS

A majority of the reviews included in this brief related to evidence generated through inclusive work with people with intellectual and developmental disabilities. There is a need to develop more evidence that identifies the facilitators of meaningful inclusion and participation of people with other types of disabilities, including women and children who are often neglected from advisory and consultative efforts within the field.