

POVERTY, HUNGER AND DISABILITY - THE MISSING LINK



First Step Towards Inclusion: Early Childhood Intervention

The fifth global webinar in the series sponsored by IFRA and IDF on 16th May 2023

In his welcoming remarks, IFRA Convenor B. Venkatesh (Venky) said, "These webinars and the advocacy which has followed have ensured that community-based rehabilitation is well and truly in the current text of the World Health Assembly resolution on "Strengthening Rehabilitation in Health Systems" being discussed from May 21-30th.

He reminded us there is still more work to do to ensure the training of mid-level and community workers in early childhood interventions are included in this resolution. Without them, children with disabilities will not be able to access inclusive education where it exists. Every day 240 million children with disabilities, 10 percent of the world's children, face various barriers that hinder their full participation in society on an equal basis with others (UNESCO).

To understand the reality of how access to these opportunities are not automatic for children with disabilities from early childhood onwards, Venky provided statistics gathered from a recent UNICEF report that showed children with disabilities are:

- ❖ 25 per cent less likely to receive early stimulation and responsive care;
- ❖ 25 per cent less likely to attend early childhood education;
- ❖ 42 per cent less likely to have foundational reading and numeracy skills;
- ❖ 47 per cent more likely to be out of primary school;
- ❖ 49 per cent more likely to have never attended school.

Given these statistics, more must be done to make inclusive education a reality for millions of children with disabilities who require early childhood intervention to enable them to participate with their age-mates in inclusive education programs.

The first presenter, **Njeri Maria**, founder of **Njeri Maria Foundation**, shared her experience on **"Evidence-based data, real-time stories and pilot environments for community-based early childhood development interventions for children with developmental disabilities in Kikuyu, Kenya."** Njeri is a diversity advocate, social inclusion expert, and trainer, who advances the lives of children and adults with cerebral palsy and their families in Kenya through awareness creation, spearheading advocacy, facilitating early intervention and support systems. She finds the biggest challenge is the lack of the right environment and systems to enable parents and caregivers to raise and take care of a child with disabilities. Her work includes using a community-based systems approach that heightens awareness inside families and communities to establish acceptance patterns and continuous interventions. These create sustainable systems and supportive environments that include community-based early assessments; professional advice; information on accessible, adaptive devices; monitoring each child's progress; networking and referrals; counseling and psycho-social support. She summarized that building such enabling environments requires capacity-building for professionals; engagement of community workers, volunteers, and leaders; and peer-to-peer workshops.

Dana Corfield, the second presenter, spoke about "Early childhood development supports for children with disabilities in Peru." In Peru, there are state-run programs, NGO programs including CBR, inclusion in state pre-schools, and private and non-profit therapy centers, yet less than 10% of pre-school children with disabilities can access any of these services. Dana is the founder and director of Equip KIDS International – a small, grassroots organization working with children with disabilities and their families. They focus on neglected areas such as family support, communication, seating and mobility. They form family groups to create supportive, caring environments that are crucial to the development and well-being of children with disabilities. This happens by addressing requirements in psychological support, practical developmental information, and connecting to available services. Dana described language, proper and adequate seating, and mobility as key features in improving each child's ability to engage with others and their environment. Equip KIDS' programming has over 20 years of experience working with families, schools, and other community organizations.

Rachel Lassman is an experienced occupational therapist, a researcher at the London School of Hygiene and Tropical Medicine, and the global co-ordinator of *Baby Ubuntu*. *She spoke about the "Early Care and Support for Young Children with Developmental Disability Program in East Africa"* which aims to improve the lives of children with developmental disabilities by empowering their caregivers and families through information sharing and peer support. The program is co-facilitated by "expert parents" and has developed a robust package of resources and workshops. Key elements of the program are paternal and community engagement, and acknowledging the financial aspects of child disability and poverty as key barriers to access an improved quality of life. Research on the program has found strong qualitative evidence of its positive impact, cost effectiveness and potential to scale-up by adapting to diverse settings and contexts. A critical finding is the importance of community engagement to embed support within government structures to increase social inclusion and access to health and education for all.

Radhika Alkazi is a child rights advocate who reports on the on-the-ground realities of children with disabilities and is the founder of *ASTHA*, a community-based cross-disability organisation. She has been working in India for 30 years running early intervention programs for children with disabilities in the urban slums of Delhi. Radhika spoke about "*Putting the child at the centre in early childhood inventions*" and shared inspiring stories from five diverse organizations spread across India. In all cases, she emphasized the importance of the first 1,000 days for early identification and intervention, and the need to address poverty, stigma, educational and geographic barriers. She explained that while the child is at the centre of these programs it is also about the inclusion of parents and families in community, the role of the state, and the right of children with disabilities to be part of all programs for young children. Radhika introduced the CBR Network, Karnataka; Anwesha, Kolkata; Vidya Sagar Rural CBR Program, Tamil Nadu; Sanchar, West Bengal; and ASTHA, Delhi. All four presentations provided concrete examples of what is being done in early childhood interventions, their successes and challenges, and the fundamental importance of Early Intervention as the first step for inclusion.

In summary, whether the presentation was from Kenya, Peru, Uganda, or India the message was clear: early childhood interventions do make a significant difference in the quality of life for children with disabilities and their families. Engagement with families, carers and the broader community is essential. Collaboration between state and local governments and respect for the needs and rights of children in their youngest years is important so that services known to make a difference are accessible. This can only be done with the true involvement of parents and carers so they have the information, training and ability to influence decisions that make a difference.

View full proceedings of the webinar here: https://youtu.be/9DkWv7_VSW0