Serving Children with Disabilities

Executive Summary

St. Catherine University and SPOON Foundation

September 24, 2016

Summary

Children with disabilities are among the most hidden populations in many countries, bearing the consequences of stigma, poverty and neglect, and Zambia is not an exception. The prevalence of disability in Zambia is between 7.2-13.0% of the whole population. The consequences of disability include, but are not limited to, isolation and stigma, poverty, co-morbidities and secondary disability, limited opportunity to participate in society (e.g. school, work, civil society) and early death.

The team from St. Catherine University and SPOON Foundation aimed to answer three fundamental questions from the desk review and the formative assessment in Zambia, June 2016. First, can the quality of life of children with disabilities living in institutions be improved? Second, what are the conditions of children with disabilities living in community? If excellent, how can those conditions be supported and expanded? If poor, how can the quality of life of children with disabilities and their families be improved? Third, are there effective strategies that can be implemented and disseminated nationally to assure good quality of life for children with disabilities?

1. *Can the quality of life of children with disabilities living in institutions be improved?*

Institutions where children with disabilities reside can be improved. One important gap for these children is that staff lack resources and sufficient training on best practices for the care of children with disabilities. This need for training around feeding and nutrition was heard and observed in orphanages and schools. Providing adequate nutrition and rehabilitative strategies could significantly improve children with disabilities' quality of life.

2. *Second, what are the conditions of children with disabilities living in community? If excellent, how can those conditions be supported and expanded? If poor, how can the quality of life of children with disabilities and their families be improved?*

   The conditions for children with disability in the community vary based on the type of disability. Regardless, children with disabilities and their parents living in the community face substantial stigma and isolation. We heard that parents who have a child with disabilities is at greater risk of spousal abandonment, has more difficulty seeking and keeping gainful employment and lacks social support by the community due to the belief that disability may be caused by witchcraft. Subsequently, parents make difficult choices – hide the child, discard the child, place the child in an institution, or risk deepening poverty. Not all families are faced with these decisions. Rehabilitation centers do exist – more so in the urban versus rural areas. Transportation becomes a barrier – both in terms of accessibility of the transportation, the size of the child, availability of equipment that supports mobility (i.e wheelchairs) and the amount of time it takes which further restricts

employment. There are opportunities for children with disabilities to attend school. The barriers include school accessibility, transportation, recognition that the child should be educated and further training of educators.

There are many organizations working with children with disabilities and supporting families, but it appears the need outweighs the capacity. Other than alleviating poverty, the next most important factor to address is the perceptions and knowledge regarding disability at the family and community level.

3. *Third, are there effective strategies that can be implemented and disseminated nationally to assure good quality of life for children with disabilities?*

Community-based rehabilitation is operational in several areas in Zambia. The model used by one site includes an interprofessional team that provides services to children and families through outreach clinics and trained outreach workers. The approach not only brings services to families in the community, it provides an opportunity for children to reach their potential and has been effective in reducing stigma. There are existing organizations that have the structure to allow the replication of this approach, including the Catholic Medical Mission Board.

The communication between organizations and government departments is also being improved. The Children in Families Initiative seems to be a very effective approach for bringing key informants across levels of practice and policy to enhance care for children and families in need. In addition, there is a strong organization (Zambian Association of Child and Youth Care Workers) who have a system/infrastructure for networking, education and mentoring. Finally, all the family, community, education, NGO and government representatives recognize the great need for children with disabilities and would like to be included in further discussions and have desire to engage with our team in the future.

Next Steps

We propose a two-pronged approach.

1) One important gap for these children is the lack of staff training and resources for working with children with disabilities. This need for training around feeding and nutrition was heard and observed in orphanages and schools. In addition, support around providing adequate nutrition and rehabilitative strategies could significantly improve their quality of life.

Therefore, we propose to address the immediate needs of children living with disabilities in institutional settings using a train-the-trainer approach for nutrition and feeding skills for children with disabilities living in institutions.

2) Stigma and isolation are important limiting factors for children with disabilities and their families. The community based rehabilitation model is an effective approach to "enhance the quality of life for children with disabilities and their families; meet their basic needs and ensure their inclusion and participation" in society (http://www.who.int/disabilities/cbr/en/).

Therefore, we propose to further strengthen relationships with existing organizations, children with disabilities and their families in Zambia to expand / enhance current models of community-based rehabilitation model.

Conversations with key organizations in Zambia have been initiated and the St. Catherine University team and SPOON Foundation are in discussion with GHR Foundations to plan for the future.

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