

Priority Support Needs of Families of Children with Disabilities in Addis Ababa, Ethiopia

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Family support: Why should we care?



- Families are an important source of support for children with disabilities for their care, development, and education
- Disability can bring both positives and negatives
- Evidence demonstrates that family supports in disability lead to improved family functioning and child outcomes

- How do family members of children with intellectual and developmental disabilities in the Mekaneyesus Centre in Addis Ababa, Ethiopia **currently meet their disability-related support needs?**
- What are these family members' most pressing **unmet disability-related support needs?**
- How does the family currently perceive their **capacity to meet their disability-related support needs?**

- Ethiopian Evangelical Church Mekane Yesus Center for Mentally challenged Children (EECMY-CMCC) in Addis Ababa, Ethiopia



- Exploratory, qualitative descriptive design
- Recruitment through Mekaneyesus Centre in Addis Ababa
- Semi-structured interviews with 16 participants, selected purposefully for representation of diverse gender, family connection (e.g., not only mother), socioeconomic background, and severity of child disability
- Interviews were audio-recorded, transcribed verbatim, translated into English
- Thematic coding (Braun & Clarke, 2006) in English and Amharic

Preliminary Findings



- What are the needs? (met and unmet)
- Who meets those needs (or have a responsibility to meet the needs)?
- Capacity of families to meet their needs?

What are the needs?



- Emotional support– Improving psychosocial functioning in terms of reducing stress and improving a positive orientation of feelings
- Physical support– Improving physical health or daily living skills of the family member with a disability
- Material/instrumental– Improving access to adequate financial resources and support for the completion of necessary tasks
- Informational support– Providing knowledge that leads to improved decision-making

Kyzar, Turnbull, Summers & Gómez, 2012

- “My family have a bad look on my child. They said don’t bring her to this house; she is my daughter; they can’t be more than her for me. Instead, they should have supported me...Nobody understands...especially my family. Surprisingly, when I take her there [family home] one day; my brother said to me 'what a dump you have brought to us'. I never forget that time...”

Participant 6

- “Nowadays, no one can reach anywhere if you don’t have someone to support you. If you have supporter, you will get up fast... I have tried to kill myself three times... I was stronger in the past. But now the magnitude of the problems and the situation make it worse.”

- “I can’t tell you the suffering I endured due to this child. Even when he is four years old, he defecates in his bed. He does not know to express when he is full and vomits. I suffered a lot!” Participant 8
- “What he needs is diaper. I told you that he uses diapers. If he passes pee on the diaper and if I have no money to buy another...we disdain that. Just to alter that soon after he release his pee I need a diaper support. His case needs treatment very much. He needs treatment more than anything.” Participant 1

- “In our neighborhood, there are no places that hold our children. If there were such centers, you will go there to take your children and you will arrive at your work early. Even now, I can bring her in time to this center. The problem is when I want to go to my work, I can’t find taxi. It would have been nice if there was something near to our houses.” Participant 7

- “When the family were looking for their daily bread, they chained their child in their house. This is adding damage to what exists. When we meet with other parents, for example, I come from separate area and another parent comes from different area. This way I have brought a lot of people to this institution.”
Participant 5

Who?



- Family members
- Professionals
- Spiritual community
- NGOs
- Community
- Home workers or servants
- Peers
- Government
- Specialized institutions

- Participants as active agents in meeting their own needs
 - Spirituality
 - “When my husband heard about the problem, he said we have to accept whatever God gives us. He said God is omniscient. Even when they said he can’t walk or talk, my husband said God will change our kids story. And indeed God has changed the story when our child started walking. The doctors just did what they learned but God changed everything” Participant 5
 - Personal coping strategies
 - “Whatever you say, I am gonna laugh. We laugh on anything and everything. And when we laugh, we laugh loudly. People say why you are laughing when you have two ‘injured’ children. They say: why you laugh out of proportion? But I say my fate in the hands of God. No one can prevent me from laughing. God will always stretch his helping hands” Participant 3
 - Sacrifice / adjustment / choosing the “least worst” among hard options
 - “I was a pharmacist. I stopped my job as pharmacist. I stopped everything related to my job. I tutor her holding her notebook and going all the way with her.” Participant 4
- Nearly all families identified a need for more support, and that all needs were not presently being met (or met in the way they would like)

Implications



- Universality of family support needs
- Context-specific considerations
 - Poverty
 - Government support
 - Religion/spirituality
- Family resilience
- Economic implications – families being kept out of the workforce

Next steps

- Completion of full analysis
- Sharing of findings
- Future advocacy, action, research direction
- Occupational Therapy community development



Questions?

