

Raising a child with intellectual disabilities in Ethiopia: What do parents say?

by

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Abstract

Parental experiences in raising children with intellectual disability in Addis Ababa Ethiopia are described. Using a qualitative research approach, interviews from eleven families formed a rich contextual data base, in addition to informal observations, informal conversations, discussions with key informants, and document review. Findings show that parents face emotional, social, economic, material challenges while raising their children. Themes related to insufficient information and training related to intellectual disability, insufficient formal/informal supports, unfavourable attitudes on the part of the society towards children with intellectual disability, worries about the future, financial problems, lack of materials. Results are discussed in terms of the socio-cultural theoretical framework as well as the salutogenic perspective that focuses on strengths and coping strategies. The author proposes that, to tap into the familial strengths, a systems approach to empowering families may be effective if traditional institutions within the society are encouraged to include families of children with intellectual disabilities.

As Africa's oldest independent country, Ethiopia covers 1.13 million sq km (437,794 sq miles) with a population of 74.2 million highly diverse people with a life expectancy of 46 years for men and 49 years for women (UN, 2005). The major languages are Amharic, Oromo, Tigrinya, Somali; major religions are Christianity and Islam. The people have a *per capita* income of US \$160 with the main exports of coffee, hides, oilseeds, beeswax, and sugarcane (World Bank, 2006).

The family comprises the largest group of caregivers due to the combination of a lack of residential services and the prevailing societal beliefs that influence families to keep their children hidden and protected at home. There are international and local non-government organizations with professionals who are dedicated to the modernization of special education. One specific reform initiative is established-- a two-year master's degree in special needs education at the Addis Ababa University (Weldeab, 2006; 1999).

Throughout Ethiopia, having an intellectual disability is regarded as a source of shame (e.g., Chernet, 2000). Misconceptions and unfavorable attitudes towards disabilities and persons with disabilities result in continued stigmatization even in the few schools where students with intellectual disabilities are included. A large number of children with disabilities have been hidden at home and kept away from schools and other intervention programs (Abreham, 1998; Tirrussew, 2005; Weldeab, 2006, 1999; Weldeab & Endrerud, 2004). Even if their coverage is very limited compared to the large number of persons with disabilities in need of services, there are educational and medical rehabilitation services for persons with disabilities in the country (Tirrussew, 2005). Encouraging and promising projects and pilot projects on inclusive education and community based interventions are also going on in some places of the country. For example, historical data reported by the Ministry of Education (2003) showed that 3, 787 children received special education and 300 teachers engaged in special education services in 1998-1999.

However, these data are likely to be inaccurate because there is no general term that can directly fit to the English term *disability* in Ethiopian languages. For example, in Amharic language - one of the languages spoken in the country, for instance, the term '*akal gudategnenet*' is used to refer to visible physical difficulties while deficits of the mind are not included. It seems that the term is just used to refer to failure of bodily organs to function in the normally expected fashion. Although the Ethiopian Proclamation No. 101 of 1994 officially defines "*disabled person*" as a person who is unable to see, hear or speak or is suffering from intellectual disability or from injuries that limit him or her due to natural or man made causes, this term is not a commonly used by the people. According to this Proclamation, the term does not include persons who are alcoholic, drug addicts, as well as persons with psychological problems.

As is the case in many developing countries, families in Ethiopia comprise the largest group of caregivers for children with disabilities. This is due to the fact that there is a lack of residential services and the vast majority of the children live with their families. The purpose of the study is to investigate the lived experiences of parents in raising children with intellectual disability in Ethiopia. The study is based on the premise

that the success of educational and other intervention programs depends to a great extent on the current experiences and fulfillment of the needs of service providers themselves – especially the parents. In the absence of sufficient information about the practical experiences (challenges, barriers and facilitators) of parents and their specific needs, for instance, it would be impossible for any service providing programs to be effective. In this study, the idea of challenging experiences encompassed both demanding and stimulating experiences.

Research Questions

The study addressed four questions:

1. What are the ideas of parents concerning intellectual disability in their child?
2. What are the experiences of parents in raising a child with intellectual disability?
3. What are the specific needs of parents in raising a child with intellectual disability?
4. What could be done to meet the needs of the parents?

Theoretical Framework

The theoretical framework for the study is based on the socio-cultural perspective of disability. The socio-cultural or ecological perspective proposed by Bronfenbrenner (1979) can be useful for understanding how disability is perceived by the people in Ethiopia, the terms they use in connection with disability, their perceptions about causes of disabilities, and the role of traditional “power-holders” in influencing perceptions about disability. For example, Weldeab (2000) found that “*labeling persons after their impairment is still common in most parts of Ethiopia. In most places, people use such terms as an insult which really have psychological impact on persons having those impairments and their families*” (p. 21).

Methods

In order to obtain the lived experiences of raising a child with an intellectual disability, the phenomenological hermeneutic tradition was used by the researcher through conducting a case study approach across multiple families, with each family constituting a case.

To obtain the *emic* perspective from the parents, a semi-structured interview guide was developed in English and translated into Amharic (prevailing language in Addis Ababa, Ethiopia, the site for this study), field tested, and slightly revised to reflect the feedback obtained from the field test. Data were collected over a 6 month period of time, where each family was visited at least twice. Each interview session was tape recorded with permission over one to one and half-hours. The order or wording of the questions, giving examples, deciding the amount of time and attention given to different topics varied-- adding questions depended on the flow of conversation as well as the characteristics of interviewees. After transcribing all the interviews and then translating the information from the local language Amharic to English, reliability checks were provided by experienced professional colleague to ensure the accuracy of the translation.

The next step of the analysis was to identify constructs, themes, and patterns (Miles & Huberman, 1994; Gall, Borg, & Gall, 1996; 2003; May, 1997; Curasi, 2001; Creswell, 2003). The individual interviews were read a number of times to identify important and notable ideas that seemed to directly relate to the research questions posed by the researcher. The information was then sorted and classified according to the major concepts or headings derived from the data itself. Then, thematic contents or emerging theme titles were formulated based on the major research questions. In other words, main categories were constructed and used to systematize the data, yielding a master list of themes which was then ordered coherently.

In the conduct of the study, Weldeab was careful to attempt to control for his own subjectivity. Following the tradition suggested by Alan Peshkin (1988) for being a responsible qualitative researcher, Weldeab looked for, and recognized, how his own biases might influence the research. For example, as an Ethiopian, he naturally looked at the data from the perspective of a native speaker of Amharic while simultaneously, his role as a doctoral student studying at a Norwegian university allowed him to look at the data from the perspective of his professional expertise. The phraseology he used to representing the themes could be considered a reflection of his empathy with the experiences of the parents and the children with respect to his perceptions of how they were coping within Ethiopian society as a whole. The methods that he used in data analysis were selected to decrease the influence of subjectivity included validity and reliability checks, providing an audit trail to connect themes to multiple sources, and looking for pervasiveness of the themes across all families.

Data Sources

Participants included in this study were ten children whose parents were interviewed -- 6 boys and 4 girls (ranging from 8 to 17 years of age) with 7 described as having moderate intellectual disability and 3 with mild intellectual disability as determined by documents of the Ethiopian mental health organizations, the description from the parents, the researcher's observation and the comparison to the characteristics of different classifications of intellectual disability in the literature (e.g., AAMR, 2002; Beirne-Smith, Patton, & Ittenbach, 2002). The majority of the parents reported the onset of the intellectual disability from birth to one who acquired the disability at age 3 and another at age 8 months. The parents who were interviewed ranged in age from 18 to 55. Education levels ranged from ability to read and write, achievement in grade school (4th, 5th, 6th, 8th, 9th, and 10th grades), diploma in accounting. Occupations ranged from housewife, to caretaker, day laborer, business man, and retiree. Socio-economic status of the families was described as poor for 8 families and moderate for the others. Family members in the household ranged from 2 to 14. Interviewees' relationships to the child ranged from parent (mother or father) to sister to care-taker. The first author was an Ethiopian national with command of the Amharic language and had the benefit of local advisors at Addis Ababa University.

Summary of Results

Although the dissertation report compared parental experiences with the experiences of teachers of the children with intellectual disabilities for those families whose children attended school as well as social workers who interacted on behalf of the families, in this paper, only the parents’ perspectives are presented. Four themes emerged. In the following section, each theme is explained, and representative verbatim remarks from parents are included to illustrate the details and content of their concerns.

Theme 1: Parents’ ideas concerning intellectual disability in their child. As shown in Figure 1, three categories emerged: a) parental ideas about causes of intellectual disability; b) parental ideas concerning potentials of the children; and c) parental ideas about possibilities of improving the condition of their children. One of the parents (Case 2), for instance, expressed her ideas this way: “*What can we do except praying to God? ...only God can improve the situation...*” and two parents stressed the possibility of improving the condition of their children if they used holy water (both parents in Case 9). Almost

 Insert Figure 1 About Here

all parents (Cases 1, 2, 3, 4, 6, 7, 8, and 9) reported that they were concerned a lot about their inability to fulfill the needs of their children as their financial situation was poor. One of these parents (Case 1) described her stressful concern and worries as follows:

... now she is growing and her needs are also growing. On the other hand, we have economical problem and we cannot fulfill all of her needs. This is really my big worry in my mind - ‘yechinkilat kusil honobignal²’ (it is a wound on my head)” ...There will be so many needs that will come along with her development...she is growing now and the difficulties we are facing are also growing and increasing...In addition, the school is located far from our place. Since we cannot afford paying for transportation, she has to stay home most of the times...they also ask you to buy uniform and other materials... Oh...

Theme 2: Social-related experiences of parents. Several social-related experiences were reported by the interviewed parents. These experiences were condensed to five sub-categories: insufficient social support, poor social network or interaction, conflict with others, unfavorable attitudes, and being stigmatized (Figure 2).

 Insert Figure 2 About Here

² Literally, this phrase means ‘a wound in mind’. People use it when they want to explain something which is a traumatic experience or something that can always stay in mind.

For instance, a mother of a girl with intellectual disability said:

I am the one who is more responsible for (child's name). It is really difficult to have and rear a child like mine. I am the only one at home who spends much time with her. ... all the burden is on me only. No one is helping me. There is also no support from the community... (Case 1)

Stigmatizing experiences resulted in a pattern of avoidance of most social interactions in order to protect their child from the larger society's negative treatment of the children and/or the family members. For instance, one of the parents (Case 2) described his experiences this way

"...sometimes when I go out with my son, some people consider him, including me, as a beggar, and sometimes they just want to throw some coins. It is really upsetting and hurting"

Similarly, another parent (Case 6) said,

"You see the stigma from the reflections of others' attitudes especially when you walk with your retarded child. It seems that they think that we are less than any normal person"

Theme 3: Coping strategies used by parents. In addition to the above parental experiences, some specific coping strategies were identified that had been used by parents to cope with the situation of having their child with intellectual disability. The coping strategies were categorized into two lines of research on stress and coping described in the literature (e.g., Dale, 1996) – *negative or emotion-focused strategy* and *positive or problem-focused strategies* (see Figure 4). For example, a parent (Case 6) said:

...this poor child has nobody except me. What will happen to her if I die? This is the question that I could not get an answer for. Nobody will take care of the way I do if I die. This worries me so much...I am a single parent and this makes me worried about my daughter because who can take care of her for example, if I get sick or something happens on me one day.

 Insert Figure 3 About Here

Theme 4: Specific needs expressed by the parents. From the expressions of the parents in the interviews, four major needs emerged as shown in Figure 4. These included needs for support, for information, for vocational training for their children, as well as need to be involved. Almost all of the parents (Cases 1, 2, 3, 4, 6, 7, 8, and 9) reported that they needed social support for their children with intellectual disability. Some parents (Cases 1, 3, and 4) emphasized a need to be supported by community. For instance, one parent

(Case 1) said, “*It would be nice if people in the community organize a kind of social support.*” Another parent (Case 3) said, “*It is better if we are given some support in our community...I think that is what other parents like me also need...*”

Other parents mentioned ideas related to their need for information and training for a vocation. One parent (Case 1) expressed her wish for more information in the following way:

...Her teachers are always telling me that she has a problem. I know she has a problem; the only thing that I do not know is the solution! In most places they can tell you that there is a problem but not the solution! ...Several people from different organizations have interviewed me at different times. But none of them come with the solution or sufficient information!

The need for their children to have vocational training was mentioned by one parent (Cases 6) who said, “*I know what my daughter needs. If she gets vocational training, she would do better...*” Another parent (Case 8) emphasized d that the child could learn better if she had the opportunity to attend training on handicrafts and sewing.

 Insert Figure 4 About Here

Discussion

In this study, the socio-cultural framework seems to provide a helpful conceptualization to interpret the results. For example, the process of labeling persons after their impairment is still common in most parts of Ethiopia and this phenomenon was evidenced by the parents who were interviewed for the current study. Even in Addis Ababa, Weldeab noted that the parents revealed how using such terms was experienced as an insult which really have psychological impact on persons having those impairments and their families (Weldeab, 2006). For example, one parent said that her son was a “*laughing stock*” and that his nickname in the community was *Mama Killo* (a legendary figure in Ethiopia known for his foolish deeds). In addition, there is the general societal tendency to generalize the existence of the intellectual disability to the family member (e.g., the mother also must be intellectually disabled) and the teacher. As stated by one teacher who was interviewed, “*Some teachers in the school think that I myself have disability like the children I am teaching*” (p. 154).

It can be said, somewhat sadly, that the parents interviewed for this study, as a whole, had limited coping resources and functioning. Other researchers have found that coping resources and functioning are mediated by protective factors in the ecological systems within which parents interact. Some of these protective factors include a supportive social network, sufficient emotional support from friends and others, favorable attitude to and perceptions of disability in the larger society (e.g., Bailey & Smith, 2000; Moor & Moor, 2003).

The integration of salutogenic concepts described by Antonovsky (1996) as well as systems theory, both of which incorporate Bronfenbrenner's (1979) socio-cultural ecological perspective, provide the conceptual context for interpreting the results. In relation to prevailing literature, the themes resonate with findings from other researchers (Ferguson, 2002; Ferguson, 2002; Kim, Greenberg, Seltzer & Krauss, 2003; Leal, 1999; Russell, 2000, 2003). In terms of the experiences of the families in Ethiopia, there seems to be some consensus in the themes with respect to raising different questions and seeing different avenues to explore with regards to raising children with intellectual disabilities.

Bronfenbrenner's (1979) ecological framework is helpful to understand the themes in terms of how people represent their everyday environments as well as in the broad range of situations encountered in their homes, schools, neighbors, and communities. The phenomenon of raising a child with cognitive disabilities is captured by the specific phraseology and expression (or "voice") of the parents, and is shown by the frequency of the themes and consistency across all eleven parents (specifically their difficulty in procuring meaningful information about the nature of the children's disabilities, the prognosis and or expectations for future development). The social experiences of the parents, for instance, imply a serious need to increase their personal networks.

 Insert Figure 5 About Here

The first author (Weldeab) applied Bronfenbrenner's ecological model is applied to the social system of Ethiopian society. As shown in Figure 5, the traditions of Ethiopian society become agents of change. Changing the Ethiopian society's prevailing beliefs and negative expectations for children with intellectual disability, the traditional institutions might be encouraged to use strategies reported in the literature such as organizing parent meetings, seminars, workshops, conferences as well as spreading information through leaflets and school media. By working within the cultural traditional institutions of Ethiopia [e.g., "*coffee mornings*"]. Utilizing traditional social institutions like "*idir*", "*equb*", "*senbet*", "*mahber*", "*baltina*", as well as "*coffee mornings*" or "*coffee afternoons*," parents' perspectives as well as the attitudes of the larger society can be changed from the stigmatized negative stereotypes that seem to pervade the society's reference to and treatment of children with cognitive disabilities towards a more strengths-based perspective.

For example, *idir* is a form of traditional social institution that is established by the mutual agreement of community members in order to collaborate with each other whenever any member or their family members face adverse situations. In these families' lived experiences, there had been no such collaboration to help them cope with raising their child, clearly an adverse situation. Feelings of shame were reported as a reason to minimize their social network for two families (Cases 3 and 9). One parent (Case 9) said, "*I even could not attend idir as I used to be. When I go there people start talking about me. I feel that they consider me as a sinful... As a result, I do not feel comfortable when I go there. I feel shame...*" Stigmatizing experiences such as this family reported thus

resulted in a pattern of avoidance of most social interactions in order to protect a child from the society's negative treatment. Nonetheless, *idir* may be the best tradition when it comes to changing the society's attitude as it usually brings together large groups of people from different religions and cultures.

For example, the tradition of *coffee mornings* involves the ritual ceremony where young girls of a family who are taught how to make and serve the 'first cup,' then the 'second cup,' and so on. Thus, *coffee mornings* are situations where parents (neighbors) meet and discuss social issues while drinking their coffee. In many cases, the main thing is not the coffee but the meeting itself because they (especially parents or women) discuss different issues and find solutions for their problems. Therefore, service providers such as social workers could come and join these neighborhood meetings to find normalized situations to explain about intellectual disability, treatment, expectations, and so on. They could host coffee mornings themselves, thus facilitating social interaction amongst a group of community people on behalf of the parents. They could organize neighborhood study groups for people who would learn about disability issues and then go out to teach others. In this way, members of the community or neighborhood (i.e., the mesosystem) can be led to change their attitudes towards disability and towards their neighbors whose children have a disability. When the society changes its attitudes, then the parents' challenges would be minimized.

In fact, Coleridge (2000) states, “...without an awareness of how disability is perceived in the target culture, a disability program does not stand much chance of being relevant or sustainable” (p. 21). This implies that, especially in Ethiopian communities where people from a variety of cultures and beliefs are living together, without the prior understanding of how the communities and families perceive those with a disability, it is very unlikely that any intervention programs can become effective without some adaptation to the traditional customs. Professionals and the traditional mediators of the society (e.g., the priests and ministers, the social workers and teachers) must understand the parents' situation and attitudes, their values and life situations. They can ally themselves with the parents to form partnerships, provide information and new understanding to them.

One of the outcomes of qualitative research is to explain the lived experiences of others. This often leads to realizations that the world is not perfect and that there are other ways to live the experience. The findings of the present study show that most of the parents who were interviewed had attributed the cause of the children's intellectual disability to God; this means that because their children represent God's will, any intervention or rehabilitation of the child is perceived to be beyond their control. This must be kept in mind when different programs (such as Community Based Rehabilitation) are recommended. If parents are taught to understand the nature of the intellectual disability and that children do grow nonetheless, they will be better prepared to access educational programs that will allow their children to grow and develop skills. Especially if collaboratively developed by the traditional institutions as represented by church officials, the programs could be valuable methods to help parents perceive their children as gifts from God.

The positive or problem-focused strategies that surfaced in this study reflect a potentially salutogenic framework (e.g., Antonovsky, 1979). Salutogenic approaches to health compared to the traditional medical model of focusing on the disease are gaining recognition in world health organizations. In this study, strategies named by some parents that could be considered salutogenic in nature include their reliance on faith (mentioned by 3 families) and their search for information (mentioned by 1 parent).

Reliance on faith or religion helped some parents to minimize the stressors of raising a child with a cognitive disability in what might be termed an environment that was predominantly hostile towards individual differences. Reliance on faith helped them deal with stress and thus seemed to empower them to better cope with the situation, as in the words of one parent, "...*We continue to pray to God and he will lead us to the solution.*" Finally, it is inspiring to note that one parent implied the benefits of this strength in her interview when she stated, "*I think I have learned a lot after I get this child. Even, my ability of solving problems in our family has increased. God gave me this child just to increase my knowledge*" (p. 147). The "voices" of families in Addis Ababa, Ethiopia, speak loudly, clearly, and, often, plaintively, about their need for education about the nature of intellectual disabilities and about their desire to find better ways to improve the lives of their children.

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<i>Causes of intellectual disability</i>		
Curse from God	Cases 1, 2, 3, 5, 9	6*
Doubtful understanding (uncertainty)	Cases 2, 6, 7, 8	4
Accident	Case 4	1
<i>Potential of the children for learning</i>		
Has no potential	Cases 1, 3, 4, 5, 7, 9	6
Doubtful understanding (uncertainty)	Cases 2, 9	3
Vocational training could help	Cases 6, 8	2
<i>Possibilities of improving the children's condition</i>		
Only God can improve it	Cases 2, 4, 5, 7	5**
Possible with vocational training	Cases 6, 8	2
No possibility	Cases 1, 3	2
Holly water could help	Case 9	2*

* = In case 9, both parents (the mother and the father) have mentioned the idea; ** = In case 2, both parents (the mother + father) have mentioned the idea

Figure 1: Parents speak about the condition of intellectual disability and their children

Social-Related Experiences	Case(s)	Number (N=11)
<i>Inadequate social support</i>	Cases 1, 2, 3, 4, 5, 7, 8, 9	8
<i>Unfavorable attitudes</i>	Cases 1, 2, 3, 6, 4, 9	6
from people in the community	Cases 1, 2, 9	3
from parents of non disabled children	Cases 3, 6, 4	3
<i>Poor social network</i>	Cases 1, 2, 3, 4, 9	5
continuous care demand of the child	Cases 1, 2, 3	3
people's unfavorable reactions	Cases 1, 2	2
feeling of shame	Cases 3, 9	2
<i>Conflict with others</i>	Cases 1, 2, 4, 6	4
<i>Being stigmatized</i>	Cases 2, 3, 6	3

Figure 2: Parents speak about social-related experiences while raising children with intellectual disability

Specific Coping Strategies	Case(s)	Number (N=11)
<i>Negative or emotion-focused strategies</i>		
self-blame	Case 7	1
trying to stop worries and concerns	Case 2	1
<i>Positive or problem-focused strategies</i>		
relying on faith	Cases 2, 4, 8	3
searching for treatment and information	Case 6	1

Figure 3: Parents speak about their coping strategies

Specific Needs	Case(s)	Number (N=11)
<i>a need for support</i>	Cases 1, 2, 3, 4, 6, 7, 8, 9	10
<i>a need for information</i>	Cases 1, 3, 7	3
<i>a need for vocational training for their children</i>	Cases 6, 8	2
<i>a need to be involved</i>	Cases 6	1

Figure 4: Parents speak about their specific needs

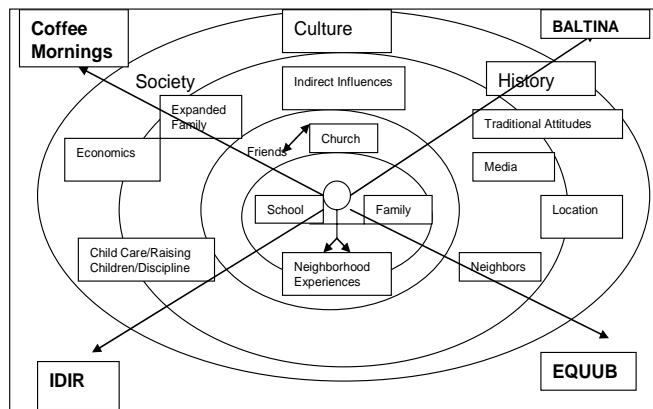


Figure 5: Implications of Bronfenbrenner Ecological Model for Using Traditional Cultural & Social Institutions to Change Societal Views of Children with Disabilities in Ethiopia