

# **The Impact of Children with Intellectual Impairment on Families: The Case of Dagbreek and Môreson Centres in the Khomas Education Region of Namibia**

**Aina Simson**

Ministry of Education, Arts and Culture  
Khomas Education Region, Namibia

**Andrew Möwes**

Faculty of Education, University of Namibia  
Windhoek, Namibia

## **Abstract**

*This qualitative study was designed to investigate the experiences, feelings and views of families with intellectually impaired children at the Dagbreek and Môreson Centres in the Khomas Education region of Namibia. For the purpose of this study, a qualitative approach was adopted. Semi-structured interviews were carried out to collect data with a sample of ten families whose children attended school at the aforementioned Centre's. The data collected was analyzed using thematic content analysis. Four sub-themes were identified and from them it was discovered that the 'overall experience of their children's impairment' by parents and guardians was unique since they had mixed feelings (both positive and negative) and had different reactions to the diagnosis of their children's impairment. The study noted that the existence of an intellectually impaired child in the family has a major impact on family members, the relationships of parents, separation of parents, extended families as well as on the public or community members.*

**Keywords:** Intellectual impairment; Trauma; Coping; Khomas Education Region

## **1. Introduction**

The birth of a child is normally viewed with eager anticipation. As parents make preparations for their child, they may not only wonder about the gender and looks of their child but they may also wonder about the child's future. When the child is born with no complications or impairments, this process seems to evolve naturally. However, when there are prenatal or perinatal complications, or postnatal discoveries of developmental impairment, the idealized picture of having a normal child is shattered (Turnbull & Turnbull, 2001). No family regardless of race, ethnicity, or socio-economic status is immune to any impairment; yet almost all are poorly prepared to cope with its occurrence (Evans, 2004). Even though there are inconsistencies and contradictory findings, in general, the available literature suggests that families of children with intellectual impairment are at risk of numerous problems in comparison to families with children without impairment (Marshak & Prezant, 2007). This is supported by Shaban,

Jevne and Sobsey (2003) who reveal that families with intellectually impaired children are confronted by challenges and bear burdens unknown to other families without impaired children.

Some of these challenges include stigma, which relates to the visibility of impairment, its perceived controllability, and its perceived danger. Stigma causes anxiety and stress in those who are stigmatized. According to Miller and Major (2000) anxiety is experienced by stigmatized people when others make sarcastic comments, or because they are excluded, discriminated against, or are the victims of violence. People who are stigmatized are almost always the target of prejudice, avoidance, and rejection. Fraser, MacGillivray and Green (1991) argue that the public have a tendency of stereotyping all those with an intellectual impairment as completely lacking in social competencies. Contrary to the above Cunningham (1996) disagrees with these findings when he stated that the child with intellectual impairment is not a burden for many families.

Families differ widely in their reactions and attitudes toward their children with intellectual impairment and it is worthwhile to consider why some families react well and others badly. Marshak, Seligan and Prezant (1999) revealed that certain periods are especially traumatic for parents of children with intellectual impairment. These include: when parents first learn or suspect that their child is impaired, age of school entry, time of leaving school and when parents become older. In order to deal with these situation parents either adapt or accept these situations. Adaptation is described as a reduction in feelings of anxiety, while acceptance is considered to be a healthy response to the fact that one's child has an impairment (Marshak et al., 1999). Existing research reveals that very often parents have a negative attitude towards their children with intellectual impairment (Gupta & Singhal, 2004). This view is supported by Grant and Whitell (2000) who said that negative attitudes adversely affect the parents. A study by Shaban et al. (2003) noted that having an impaired child had influenced some parents not to take a new job (in a new area) if the current service system was working for their child. Family members of intellectually impaired children are often perceived to experience harmful psychological effects that might lead to depression and marital dissatisfaction (Mak, Ho & Law, 2006). In addition, Gupta and Singhal (2004) supported the idea by saying that the existence of the intellectually impaired child in the family includes financial strains, prolonged dependency in basic care, continuous attention and heavy demands on the family's time and energy through needing continuous supervision to keep the impaired child out of danger. Many researchers, along with many families themselves, have rejected these negative notions (Shaban et al. 2003; Jones & Passey, 2003; Gupta & Singhal, 2004).

Siblings too have been shown to be affected by the presence of a brother or a sister with an intellectual impairment. Similar to their parents, siblings share in the anticipation and excitement of a new child in the family. According to Swenson (2005) siblings' actions towards the impaired child are usually connected with the parents' reactions towards the impaired child. If the parents accepted their child's impairment then the siblings will accept it.

Personal accounts from siblings suggest that although many siblings cope well, others may be 'at risk' psychologically and again may adopt a number of roles (Moores, 2006). On the other hand, siblings in families with intellectually impaired children often express feeling neglected or jealous because of the extra attention perceived to be paid to their impaired sibling (Jacques, 2003).

Siblings can experience this positively or negatively (Swenson, 2005). Swenson also noted that where siblings' experience is negative, it is in fact the older siblings who appear to be vulnerable, perhaps because of the extra child care undertaken by them. On the other hand, some siblings may feel that they have been harmed and expressed feelings of guilt, shame and embarrassment (Jones & Passey, 2003). It can, therefore, be concluded that the impact of intellectually impaired children on siblings varies according to the background, culture and personality traits of individual siblings.

Research on the impact of intellectually impaired children on the family provides evidence that support from the extended family gives a buffer that contributes to coping with an intellectually impaired child (Trute, 2003). Parents of intellectually impaired children often rely on the extended family members to provide care and support for a child with intellectual impairment. Ylven, Bjorck-Akesson and Granlund (2006) maintain that broadly based support systems are composed of friends of all ages, neighbors, co-workers, and others in the community who offer family resources, emotional aid, models of behavior and sources of information.

This was further supported by Green (2001) when he stated than more relatives, friends or neighbours, grandparents are a common source of assistance for families with an intellectually impaired child. Having a child with intellectual impairment may also cause some negative, or even disruptive, changes between the child's parents and grandparents and other family members. Parents may receive less support from the child's grandparents, especially those who are paternal. Drawing from the foregoing literature, this paper provides qualitative, narrative data on the experiences, feelings and views of families with intellectually impaired children at the Dagbreek and Môreson Centres in the Khomas Education region of Namibia.

## **Method**

### **Research design**

The study employed a qualitative, descriptive phenomenological approach. Qualitative methods attach importance to individuals' subjective experience and how they understand events in their lives (Gay, Mills & Airasian, 2009). This design was appropriate for the study as the researcher aimed to gain understanding of the families' experiences of having an intellectually impaired child. In addition, a qualitative method allowed the researcher to examine the experiences of the parents as understood through their own words.

### **Population**

The population of the study was made up of families with intellectually impaired children at Dagbreek and Môreson Centres in Windhoek in the Khomas Education Region of Namibia.

There were one hundred and ten (110) families with intellectually impaired children at the Dagbreek Centre while there were one hundred and twenty (120) families at Môreson Centre when the study was conducted.

### **Sample**

The researchers made use of purposive sampling. There are different types of purposive samples. The critical case sampling was utilized for this study. It has to be noted that critical-case sampling is a type of purposive sampling that involves selecting cases that are believed to be particularly important for the study at hand (Johnson & Christensen, 2008). Critical-case sampling was done so that the samples represent the above mentioned population and are unbiased.

Samples were drawn from families with children with moderate to severe cases of each of the following conditions associated with intellectual impairments, namely: Down's syndrome, Autism, Epilepsy, Trauma and Foetal Alcohol Syndrome as per the comprehensive list provided by these centres. Children of the participants ranged from ten to sixteen years in age. The researcher chose 10 families who had a child with one of these listed impairments as participants for the study. The samples included five families at each of the two centres.

### **Research Instrument**

The data for this study were collected through interviews. Interviews are aimed at exploring participants' experiences, feelings and views (Johnson & Christensen, 2008). There are different types of interview methods that can be used to collect qualitative data. The researcher used standardized open-ended interviews to get views and opinions on the phenomenon to be studied. The standardized open-ended interview was used because the method allows all respondents to answer the same questions, thereby guaranteeing comparability and consistency of interviewees' experiences. Another reason was that the standardized open-ended interview reduces interviewer effects and bias when several interviewees are involved (Gay et al., 2009). During the interview session, the researcher tape recorded the data that was then transcribed and later used in the analysis and data presentation.

### **Procedure**

A letter requesting permission, outlining the purpose of the study and its significance was sent to the Permanent Secretary of the Ministry of Education, Director of Education, and Principals of the selected centres. After identification of potential participants at the two centres, participants were contacted telephonically and informed about the purpose of the study. After consent was obtained from the participants, interviews were conducted with parents/ guardians who had intellectually impaired children in their families/households. For comfort and convenience, participants were interviewed at their homes. The researcher used an audio-recorder to collect all data.

### **Data analysis**

The audio tapes were transcribed verbatim and participants were assigned pseudonyms in order to respect anonymity. The transcripts were then analysed using the content analysis method to identify the theme and sub-themes arising from the data. In accordance with the core theme, impact on relationships, the following four sub- themes were then identified: a) Public/ community, b) Parents/Couples, c) Siblings, d) Extended Family that emerged from the subsequent creation of categories and coding of the transcript

data. The content analysis method is a method of data analysis where a researcher is central to the analysis of information gained (Gorman & Clayton, 2005). Participants’ verbatim quotes were used as low- inference descriptions to support the sub-themes and categories identified.

## Results and Discussion

In this section, the researchers presented the results according to the sub- themes and categories, in each case providing narrative examples. The following questions were asked to find out if parents and guardians experienced any problems concerning discrimination of the impaired children and whether the intellectually impaired children affect relationships between couples, among siblings and the extended families. The questions that were put forward to the parents and guardians were:

- a) Have you experienced any problems relating to discrimination towards the impaired child? If so, from whom?
- b) In what ways does having an intellectually impaired child affect the relationship between you as couples, among siblings and the extended families?

Information obtained from parents and guardians indicated that discrimination and negative attitudes of the public were displayed towards their intellectually impaired children in the following sub-themes: experiences relating to *public/ community*, experiences relating to *parents/couples*, experiences relating to *siblings*, experiences relating to the *extended family*. An example of how the core- theme, sub-themes and categories were assigned can be seen in table 1.

**Table 1: Core theme, sub-themes and categories identified from the transcripts**

Core Theme	Sub-themes	Categories
Impact on relationships	Experiences relating to Public/ community	Occasional negative attitude/behaviour, initial negative reaction but later accepted and accepted within the community.
	Experiences relating to Parents/Couples	None widowed/ adopted by grandmother, both love and accept child, support and unity, father support; loves and accepts child (single mother), father’s relationship to child ambivalent and father abandoned family; blames mother.
	Experiences relating to Siblings	Love, acceptance, jealous about preferential treatment, support, and initially afraid but later accepted, resentment; not supportive and rejection.
	Experiences relating to Extended Family	Positive relationship; love and support, negative attitude of some family members, full support; adoption and presence.

### **Sub-theme one: Experiences relating to public/ community**

The categories identified under this sub-theme were: *occasional negative attitude/behavior; initial negative reaction but later accepted and accepted within the community.*

#### **Occasional negative attitude/ behavior:**

Seventy eight percent of parents and guardians were affected by occasional negative attitudes of the public towards their intellectually impaired children. The following excerpt could best illustrate the negative attitudes of the public.

*‘At times, out there, people look at my son and pass bad remarks such as: Can such a big boy behave like a five year old child? He needs to be beaten to stop it.’*

This finding was supported by Miller and Major (2000) who reported that anxiety is experienced by those people who are stigmatized when others make derisive comments or because they are excluded and discriminated against. It appears that families with an impaired child almost always live under stress of being humiliated and socially stigmatized by the community. As mentioned in the quotation above some community members do pass negative comments on an impaired child. In addition, negative attitude towards the impaired child from the public/ community not only impact negatively on the child but also adds to the existing stress levels of the family. Such comments by the community might lead parents and guardians to feel as if they have been robbed of a chance to have a normal child, as well as their inability to be perfect parents or guardians. In all, the findings suggest that the pain associated with this feeling can be equated to some form of bereavement. It is suggested that awareness-raising activities should be particularly focused on the formation of advocacy groups representing impaired children.

#### **Initial negative reaction but later accepted**

Eleven percent (11%) initially had negative reactions towards the impaired child but was later accepted by the public. Another parent (mother) said:

*‘I did not experience any discrimination as such. Sometimes when he plays with other children, they tend to be irritated by his behaviour. He repeats things for a while before he moves on to the next play.’*

This finding is supported by the findings by Grant and Whitell (2000) who stated that negative attitudes adversely affect the parents. The message underscored here is that lack of public awareness about the potential of impaired children often acts as a barrier to their acceptance and even their participation in social events. Quite heartening, is that parents and guardians seem not to view their children as a burden; instead they are willing to resolve the situation more positively and overcome the situation graciously. Again, the problem of negative comments towards the impaired child by the public requires educational campaigns whose objectives are to make the public understand the problems of families with impaired children. Once this is achieved, the public could then shift from its negative stance to a positive perception of the impaired children.

#### **Accepted within community**

The third reaction was that of acceptance within the community. Eleven percent was accepted by the community. This was revealed in the following excerpts:

*“The child is accepted within the family and in the community. I haven’t noted anything strange.”*

*“She greets people, especially when we go to the supermarket. She will greet almost everyone in that shop. Almost all people return the greeting from her”*

These findings illuminate the findings by Marshak et al. (1999) who indicated that acceptance is used to describe what is considered to be a healthy response to the fact that one’s child has an impairment.

This was further supported by Cunningham (1996) who stated that the child with an intellectual impairment is not a burden at all. The deduction here is that the idea of acceptance implies recognizing a child’s impairment and displaying sympathetic attitudes towards the family. Thus, parents and guardians, in turn, view their children’s shortcomings realistically. In addition, it enables them to discuss issues of impairment without shame. However, in the process, parents and guardians could be devoting much attention to their impaired children while neglecting other children.

### **Sub-theme two: Experiences relating to parents/ couples**

The categories identified were: *no negative attitude (widowed/adopted by grandmother); both love and accept child; father support; loves and accepts child (single mother); support and unity; father’s relationship to child ambivalent and father abandoned family, blames mother.*

#### **No negative attitude (widowed/ adopted by grandmother)**

The first issue was that of no negative attitude (widowed/ adopted by grandmother) by about one third (30%) of parents and guardians. Parents and guardians were inspired and strengthened by the fact that they are single parents (widowed grandmother adopts the impaired child). Their responses were reflected in the following remarks:

*“My husband passed away long ago. She is just my grandchild whom I adopted and I love her dearly.”*

*“His father passed away when he was four years old but he liked his son with his condition.”*

*“My wife passed away long back when she was five years old and she loved her so much.”*

*“My husband passed away long ago. She is just my grandchild whom I adopted and I love her dearly.”*

This finding mirrors the findings by Shaban et al. (2003); Jones and Passey (2003), who described that positive attitudes help to bolster psychological and physiological consequences of stress. In all, the situation portrays acceptance of the impaired children and providing support. It appears that having an impaired child can also be a challenge which strengthens the parents and guardians of such child.

However, having an impaired child can affect them negatively because of the burden of care, although positive attitudes towards the problem could overcome the stress associated with the care.

#### **Both love and accept child**

Twenty percent indicated the presence of love, support and unity amongst couples. This was revealed in the following comments:

*“No, all is well because even the father has accepted her as god’s gift. My husband always feels bad when he noticed that someone has beaten his daughter because of her condition and she cannot fight back.”*

*“Basically there is no impact because my wife and I love her so much. We accepted her the way she is.”*  
The deduction here is that parents and guardians have reached a point of acceptance which implies that they understand the challenge of care. This enables parents and guardians to open up and discuss their problems freely. As a result they may be able to provide for the needs of the child. It appears that they spend most of their time in taking care of and providing training for their child to learn basic daily life skills.

### **Father support; loves and accepts child (single mother)**

The third category was that of a situation where the father supported; loved and accepted the child who was brought up by a single mother. Another 20% confirmed that the father support and love the children raised by single mothers. Illustrating support, some of the typical responses were as follow:

*“I do not have difficulties really. His father supports him because he stays with him.”*

*“Am not with his father but he is helping him (his son) and loves him too.”*

These findings are consistent with the findings by Cunningham (1996) who stated that the child with intellectual impairment is not a burden. In all, it appears that some parents and guardians viewed the impaired child as part and parcel of the family. The indication is that the relationship between them becomes stronger and provides an environment of team work and hence improved understanding between them. Thus, the picture here is that impaired child is not perceived as a burden but rather as a recipient of family care.

### **Support and unity**

The fourth category under this sub-theme was that of support and unity between the couples. Ten percent highlighted this category. One parent (father) said:

*“No effect because my wife and I are supporting each other”*

The findings are in line with the findings by Shaban et al. (2003), who revealed that families of intellectually impaired children are confronted by challenges and bear burdens unknown to other families without impaired children. Clearly, spousal support in the care of the impaired child gave a strong bond to the marriage and provides an atmosphere characterized by good communication.

By so doing, the impaired child is accepted as a member of the family system, whose welfare is taken care of. Perhaps, the patience shown in the parental acceptance of the child could be based on a strong understanding of the impairment. Thus, this could serve as a source of comfort for the parents and be helpful in creating a positive perception of the impairment.

### **Father’s relationship to child ambivalent**

The fifth response was that of a situation where the father’s relationship to the child was ambivalent. It was evident from the findings that the father did not play an effective role in the care of the child.

One parent (mother) said:



*“Her father did not really accept her condition although he does not say it loud. At times one can just see how he speaks to the child.”*

It can be interpreted that men may practice withdrawal, suppress feelings, and try to keep others from knowing how bad things are, while women seek strategies that help them to reach out to others, are more involved in caring activities and express feelings openly with other people especially to those with children in the same condition. It is suggested that in order to compensate for non-performance of duties as fathers, fathers could engage full-time caretakers to care for their children.

### **Father abandoned family; blames mother**

Ten percent experienced total rejection of the intellectually impaired children by their biological fathers. This was revealed in the following comments:

*“The father of my son didn’t take it well as I did. He was the weak one and didn’t bring his side as a father. He pushed everything away to me. He blames me for the child’s condition.”*

*“He told me that his son was born normal, what could have happened to him? He refuses to understand the situation of our son; as a result he went away till today. We broke up. I am the only one who is looking after him.”*

The message here is that parents and guardians felt that their child was placing greater restriction on family life. Extra care required by an impaired child appears to be pushing away fathers. The implication is that should the problem remain unsolved, it remains a stressor. It is suggested that parents could use spousal support and participation in parents groups in order to go through challenges of care. All these findings portray the findings by Gupta and Singhal (2004) when they stated that the existence of the intellectually impaired child in the family brings about a number of strains; poor communication, not accepting the situation, denying the situation, not expressing or hiding emotions, and acting in ways that break down relationships and destroy trust. Paralleling this finding is a study by Mak et al. (2006) who reported that family members of intellectually impaired children are often perceived to experience harmful psychological effects that might lead to depression and marital dissatisfaction.

### **Sub-theme three: Experiences relating siblings**

The categories identified were: *Love; acceptance and support; jealous about preferential treatment; initially afraid but later accepted; resentment; not supportive and rejection*. Fifty five percent of parents and guardians of intellectually impaired children confirmed that love, acceptance and support existed amongst some siblings, while 18% indicated that some siblings complained about preferential treatment of the intellectually impaired children by parents and guardians. Nine percent (9%) of parents and guardians indicated total rejection by siblings. Another 9% revealed that siblings were initially afraid but later accepted the impaired child. An equal percentage (9%) showed complete resentment of the impaired child.

### **Love, acceptance and support**

The first response was that of love, acceptance and support by the siblings reported by more than half (55%) of parents and guardians. This was revealed in the following excerpts:

*“Everything is fine because siblings have accepted him.”*

*“Siblings love him so much.”*

*“All her siblings love her.”*

*“The siblings accepted her as she is and they assist her all the time. When I am not around they take turns to help her.”*

*“All his siblings love him. They always play together.”*

*“She is a friendly child. Wherever she goes, she is like a teacher to other children.”*

This finding was supported by Swenson (2005) who reported that siblings’ actions are usually connected with the parents’ reactions towards the impaired child. If the parents accepted their child’s impairment, then the siblings will accept it too and adjustment will be dependent on what kind of attitude their parents have. It appears that some siblings displayed a genuine concern for their impaired siblings. This could mean that those siblings who co-operate with impaired siblings do respond to natural bonds of birth and the culture of upbringing of that family. It can be deduced, therefore, that siblings possibly do not enjoy their childhood as they have to care for their impaired siblings.

### **Jealous about preferential treatment**

The second response was that some siblings who displayed jealousy about the perceived preferential treatment of the impaired child and this was reported by less than one fifth (18%) of parents and guardians. Some of the comments made by parents and guardians were:

*“My daughter feels that only my son gets most of the attention. She is always jealous because I take his side especially when they are fighting. It makes her angry sometimes.”*

*“Some of the siblings do not like her much when she is protected by her father.”*

This is in line with Jaques (2003) who explained that siblings of children with impairment often express feelings of neglect or jealousy because of the perceived extra attention paid to their impaired siblings. This assertion was also supported by Jones and Passey (2003) when they stated that siblings may feel harmed and express feelings of guilt, shame and embarrassment. The deduction here is that an impaired child can affect his/ her siblings in different ways, both favourably and unfavourably. The unfavourable effects may occur because parents may pay more attention to the impaired child and neglect other children in the family.

It must be appreciated that parents usually tend to protect children who are viewed as weaker as a way of compensating for the impairment. It is suggested that parents could start communicating with their non-impaired children by giving them simple explanations about their sibling’s impairment in order to ease such feelings of jealousy.

### **Initially afraid but later accepted**

Nine percent of the respondents revealed that siblings were initially afraid but later accepted the impaired child. One parent (mother) explained:

*“My daughter used to be afraid of him but now she has accepted him after I explained that he is her brother and he will not harm her. Most of his siblings used to be afraid of him but later they get use to him.”*

This finding is consistent with the findings by Moores (2006), who stated that whilst many siblings cope well, others may be at risk psychologically. The message communicated here is that parents could explain the impaired children’s condition to the siblings and make them understand their sibling’s situation in order for them to adapt to challenges posed by the impaired sibling. It is clear that, if parents took an optimistic and caring way, then siblings are more likely to do the same. Accordingly, it is suggested that siblings could develop an interest in assisting the impaired child, if the principle of positive reinforcement is applied.

### **Resentment**

The fourth issue was one of resentment. Nine percent of siblings did not support their impaired sibling. One parent (father) said:

*“Brothers and sisters are always forced to take care of her. They do not make any effort to assist her on their own.”*

The deduction here is that siblings may have limited understanding of challenges of their impaired sibling. When siblings are not informed of their sibling’s challenges, they may develop negative feelings about the impaired sibling that would also add on to the existing stress levels of the family.

It is suggested that there should be open communication within families, in order to reduce the unpleasant behaviour in siblings. In addition, provision of information could be made an ongoing process in order to minimize siblings’ negative attitude towards the impaired child.

### **Not supportive and rejection**

The fifth issue was that of rejection. Another nine percent of the respondents indicated that few siblings totally rejected the impaired sibling. A parent (mother) said:

*“It became obvious when she joins other children to play, others are pushing her away. They feel that she is not part of them. You just find her standing watching others playing and none of them is talking to her. She always looks lost among others. This experience worries me.”*

This is in line with the findings by Gupta and Singhal (2004) who noted that having a child with impairment not only affects the parents but also the siblings. So it appears that some siblings are not sympathetic with the impaired child as they do not want to assist on their own. They only grudgingly assist the impaired sibling when they are reminded to do so.

It is suggested that parents and guardians could always look at the few instances where the siblings sometimes do offer little help. Once this is noted, the action should be appreciated by thanking them in one way or the other. This kind of practice will in the long run, indirectly change the negative attitude of siblings to a positive one.

#### **Sub-theme four: Experiences relating extended family**

The responses to the questions on the extended family focused on the following categories: *positive relationship, love and support; negative attitude of some family members; full support, adoption and presence*. Sixty two percent of parents and guardians of intellectually impaired children stated that a positive relationship prevailed between the extended family and their families. Thirty percent (30%) displayed a negative attitude towards the intellectually impaired children.

#### **Positive relationship, love and support**

Sixty two percent of parents and guardians of intellectually impaired children stated that a positive relationship prevailed between the extended family and their families. One parent (mother) said:

*“Every member in the family loves her and assists where they can.”*

This finding was supported by Green (2001) when he stated that more than relatives, friends or neighbours, grandparents are a common source of assistance. The deduction here is that the extended family sympathized with not only the impaired child but also the parents and guardians. This gives an assurance to parents and guardians as they are likely to view the child as ‘normal’ in spite of the impairment. Hence, the relationship bears a powerful positive impact. Such an encouragement could possibly make parents and guardians remain anxious about remaining alive long enough to provide care for their children. In all, the situation reflected a relationship of togetherness which makes parents and guardians to open up in terms of challenges they face in the care of their children.

#### **Negative attitude of some family members**

Thirty percent (30%) of parents and guardians of intellectually impaired children stated that a negative attitude was displayed towards the intellectually impaired children by the extended family. The following excerpts could best illustrate the responses of parents and guardians:

*“Some of my family members feel that he demands most of the things in the family although he is big.”*

*“There are times that you will find one or two family members doing something towards the child which is not pleasing.”*

*“Some people do not accept her condition in the family after the accident.”*

*“People from her mother’s side (mother’s family) do not accept her at all.”*

This finding is in line with the findings by Green (2001) when he pointed out that having a child with intellectual impairment may cause some negative, or even disruptive, changes between the child’s parents, grandparents and other family members. Clearly, the extended family, particularly, from the mother’s side rejected the impaired child. Perhaps, they could be busy with their own problems and find having to care for the impaired child to be too much work. It is quite painful that parents and guardians must attend to their own challenges and at the same time face the negative reaction of the extended family. In respect of the impaired children, parents and guardians may view the negative attitude of the extended family with considerable pain and despair. Overall, when the extended family fails to support the impaired children, this in fact adds to the family’s burden. It is suggested that the extended family

should assume a more positive role by providing the impaired child with access to services within the community through their own contacts with others.

### **Full support, adoption and presence**

This response was given by less than one tenth (8%) of parents and guardians. A parent (mother) said: *“basically there is no problem because most family members sympathize with him and support him especially his grandmother (his father’s mother).”*

*“My family accepts her and they support her.”*

This view tallies with the findings by Ylven et al. (2006) who noted that broadly based hands on support systems are composed of friends of all ages, neighbours, co-workers, and others in the community who offer family resources, emotional aid, models of behaviour and sources of information. It is clear that the support and acceptance from the extended family make parents and guardians feel as if others have accepted their children as they are. This leads to a sense of hope in the care of their children. In this respect, such families could experience lower levels of stress and enables them to discuss issues of the impairment with their children.

### **Conclusion**

The study was concerned with the experiences, feelings and view of families with intellectually impaired children at the Dagbreek and Môreson Centres in the Khomas Education region of Namibia. The ‘overall experience of their children’s impairment’ by parents and guardians was unique since they had mixed feelings (both positive and negative). The study noted that the existence of an intellectually impaired child in the family has a major impact on family members, the relationships of parents, separation of parents, extended families as well as on the public or community members. The majority of parents and guardians had difficulties with their intellectually impaired children in terms of the heavy demands of care. In some cases, the situation was worsened by the existence of multiple medical problems and the fact that most parents were unemployed.

Parents and guardians noted discrimination or stigmatizing practices from members of the community through negative comments and behaviour towards the intellectually impaired children. The study, to some degree, confirms and adds narrative depth to the findings of other research in the area.

Demonstrating that the impact of having a family member with an intellectual impairment is not necessarily or completely negative should not only support more positive attitudes towards people with disabilities, but encourage families who face the challenge of raising a child with impairment.

### **References**

- Cunningham, C. (1996). Families of Children with Down syndrome. **Down Syndrome Research and Practice. 4 (3), 87-95.**
- Evans, G.W. (2004). The environment of childhood poverty. **American Psychologist, 59, 77- 92.**
- Fraser, W.I., MacGillivray, R.C. and Green, A.M. (1991). **Hallas’ – Caring for people with**

- mental handicaps.** 8th edition. Oxford: Butterworth Heinemann.
- Gay, L.R., Mills, G.E., & Airasian, P. (2009). **Educational Research: Competencies for Analysis and Application.** New Jersey: Pearson Education.
- Gorman, G. E., Clayton, P. (2005). **Qualitative research for the information professional: A practical handbook.** London: Facet Publishing.
- Grant, G. & Whittell. B. (2000). Differentiated Coping Strategies in Families with Children or Adults with Intellectual Disabilities: The Relevance of Gender, Family Composition, and the Life Span. **Journal of Applied Research in Intellectual Disabilities, 13, 256-75.**
- Green, S.E. (2001). Grandma's hands: Parental perspectives in families of the importance of grandparents as secondary caregivers in families of children with disabilities. **International Journal of Aging and human Development, 53, 11-33.**
- Gupta, A. & Singhal, N. (2004). Positive Perceptions of children with disabilities. **Asia Pacific Disability Rehabilitation Journal, 15, (1), 22-35.**
- Jacques, R. (2003). Family Issues: Family dysfunction and increasingly recognises the successful, resourceful ways in which families adapt and provide care. **Psychiatry 2, 9.** New York: Medicine Publishing Company.
- Johnson, B. & Christensen, L. (2008). **Education Research; Quantitative, Qualitative and Mixed Approaches.** 2<sup>nd</sup> Edition. Pearson Education. New York.
- Jones, J. & Passey, J. (2003). Family Adaptation, Coping and Resources: Parents of Children with Developmental Disabilities and Behaviour Problems. **Journal on Development Disabilities, 11, 1.**
- Mak, W. W. S., Ho, A.H.Y. & Law, R.W. (2006). Sense of Coherence, Ways of Coping, and Well-being of Married and Divorced Mothers of Children with Autism in Hong Kong. **Journal of Applied Research in Intellectual Disabilities, 157-167.**
- Marshak, L. E. & Prezant, F. (2007). **Married with Special Needs Children: A Couple's Guide to Keeping Connected.** Bethesda, MD: Woodbine House.
- Marshak, L. E., Seligman, M. & Prezant, F. (1999). **Disability and Family Life Cycle.** New York: Basic Books.
- Miller, C.T., & Major, B. (2000). **Coping with Stigma and Prejudice.** (4<sup>th</sup> ed.). New York: Guilford Press.
- Moore, D. (2006). **Education of the Deaf: Psychology, Principles, and Practices.** Boston: Houghton Mifflin.
- Shaban, K., Jevne, R.F. & Sobsey, D. (2003). Hope in families of Children with Developmental Disabilities. **Journal on Developmental Disabilities, 10, (1), 22-40.**

Swenson, S. (2005). Families, Research, and Systems Change.

**Mental Retardation, 43, 365-368.**

Trute, B. (2003). Grandparents of children with developmental disabilities:

Intergenerational support and family well-being. **Families in Society, 84, 119-126.**

Turnbull, A.P. & Turnbull, H.R., (2001). **Families, Professionals and**

**Exceptionality** (4<sup>th</sup> ed.). Upper Saddle River, NJ: Merrill/ Prentice Hall.

Ylven, R., & Bjorck-Akesson, E. & Granlund, M. (2006). Literature review of

positive functioning in families with children with a disability. **Journal of Policy and Practice in Intellectual Disabilities, 3, 253 – 270.**