

RESILIENCE CHARACTERISTICS OF FAMILIES WITH CHILDREN WITH SEVERE OR PROFOUND INTELLECTUAL DISABILITY

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The aim of this study was to explore family characteristics and resources that assisted families to adapt after their children had been diagnosed with severe or profound intellectual disability. A qualitative research approach with a cross-sectional design was used, as the study was focused on participants' experiences. It was found that spiritual resources and reformulation of the crisis helped families to reframe their experiences with a more positive outlook. Social support from the family networks, friends and the community, and positive family characteristics, such as perseverance and humour, also contributed to family adaptation and well-being. Good planning regarding daily activities, as well as for their children's future, was also deemed important.

## RESILIENCE CHARACTERISTICS OF FAMILIES WITH CHILDREN WITH SEVERE OR PROFOUND INTELLECTUAL DISABILITY

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### INTRODUCTION

According to the American Association of Intellectual and Developmental Disability (AAIDD), an intellectual disability is characterised by significant limitations in both intellectual functioning (intelligence) and adaptive behaviour (conceptual, social and practical skills). Four categories of intellectual disability are distinguished, namely mild, moderate, severe and profound (Schalock, Borthwick-Duffy, Bradley, Buntinx, Coulter & Craig, 2010). The prevalence of intellectual disability varies worldwide, from between 1% and 3% in the general population (Harris, 2006), and is further delineated into mild (85%), moderate (10%), severe (4%) or profound (2%) intellectual disability (Sadock, Sadock, & Ruiz, 2009).

Individuals with severe intellectual disabilities have constraints in conceptual skills related to reading, writing, time, money and numbers, and need support with problem solving throughout their lives (American Psychiatric Association, 2013). Their language skills are limited, with a strong emphasis on using language for socialisation, but hardly ever used to explain something. Children with severe or profound intellectual disability (CSPID) need support with all daily activities, like eating, dressing, bathing and other bathroom needs, as well as day-to-day supervision (American Psychiatric Association, 2013). When CSPID have additional motor and sensory disabilities, the combination of disabilities can be so severe that these children cannot be accommodated in special schools (Orlove, Sobsey & Silberman, 2004). Consequently, these children often go to day-care centres that are specially designed to accommodate their needs. According to Statistics South Africa (SSA, 2005), the resources available to families and children with disabilities in South Africa are very limited. Therefore, these families are compelled to assume care of their children themselves with little formal support, and are fully responsible for the costs of professional services – placing additional pressure and stress on the functioning of the family unit.

Caring for CSPID leads to stress that influences all members of a family physically, emotionally, cognitively and socially (Pelchat & Lefebvre, 2004). The parents experience fear of the prognosis, worry and anxiety about the future, and feelings of shame, guilt, stigmatisation and social rejection (Azar & Badr, 2006; Pelchat & Lefebvre, 2004). Other stressors burdening families with CSPID include additional financial expenses, sleep disorders, unemployment and social isolation (Davies & Honeyman, 2013). Caring for CSPID is a lifelong process that not only affects all members of the family, but also the internal and external relationships of the family unit (Mak & Ho, 2007; Tadema & Vlaskamp, 2009). For the purposes of this study, the presence of CSPID in a family unit was therefore regarded as a continuous family crisis.

Family resilience is the ability of a family unit to bounce back from significant adversity through successful adaptation within the context of stressful events (Masten, 2011). McCubbin and McCubbin (1996) developed the Resiliency Model of Family Stress, Adjustment, and Adaptation. According to this model, there are several factors that play a role in a family's adaptation when facing a stressor. These include the severity of the stressor, the vulnerability of the family, and the family's established patterns of functioning. This study was conceptualised and designed according to McCubbin and McCubbin's (1996) model of family resilience.

A severe stressor, like having a child who has a disability, can cause a disruption in a family's established patterns of functioning, which then leads to a crisis within the family unit (Azar & Badr, 2006; Davies & Honeyman, 2013; Mak & Ho, 2007; Pelchat & Lefebvre, 2004; Tadema & Vlaskamp, 2009). This

necessitates change within the family's established patterns of functioning. This change marks the beginning of two different, but interdependent, processes: namely, adjustment and adaptation. In the adjustment process, factors are emphasised that protect the family against the impact of a stressor. These include social support, cohesion, financial stability, flexibility, hardiness, shared spiritual beliefs, open communication and traditions. On the other hand, the adaptation process deals with a crisis within the family unit – a stage of unbalance, disharmony and disorganisation (McCubbin & McCubbin, 1996). Recovery factors play an important role in adaptation and enable the family unit to bounce back from the impact of the stressor. The adaptation process requires that the family make use of internal and external resources to protect and strengthen the family unit (McCubbin & McCubbin, 1996).

In previous resilience studies on families with a child who has a disability, various characteristics and resources were identified that helped families to adapt and continue with their lives (Ahlert & Greeff, 2012; Bayat, 2007; Croot, Grant, Mathers & Cooper, 2012; De Klerk & Greeff, 2011; Greeff & Nolting, 2013). Two international studies regarding resiliency in families with a child with an intellectual disability were found in the literature (Gerstein, Crnic, Blacher, & Baker, 2009; Grant, Ramcharan, & Flynn, 2007), but no South African studies. Furthermore, no study on resilience in families with a child diagnosed with a severe or profound intellectual disability was reported. However, a few studies were reported that focused on coping strategies of such families (Croot *et al.*, 2012; Grant & Whittell, 2000; Taanila, Syrjala, Kokkonen, & Jarvelin, 2002), but the researchers did not report on the resilience or the adaptation of these families.

Consequently, this study's research question is: What are the qualities and resources utilised by families with children with severe or profound intellectual disabilities? Therefore the aim of this study was to identify and describe characteristics and resources that helped families to adjust and adapt after their children had been diagnosed with a severe or a profound intellectual disability.

## **RESEARCH METHODOLOGY**

In this exploratory study, a once-off cross-sectional research design was utilised to answer the research question. Data were collected on only one occasion and the answers that the participants gave on that specific day were used for the data analysis (Graziano & Raulin, 2010). A qualitative research method was used to identify resilience characteristics in families with children with a severe or profound intellectual disability. The qualitative research approach enabled us to investigate difficult and sensitive issues, since trust had developed between me (first author) and the participants (Griffin, 2004). The participants were asked only one open-ended question and both parents (11 couples) were present during each of the interviews.

## **PARTICIPANTS**

The sample in the current study consisted of two-parent families with a child with severe or profound intellectual disability. Contact was made with two day-care centres run by non-governmental organisations in the Boland district in the Western Cape province of South Africa. These day-care centres, which served 20 and 40 children respectively, specialised in children with severe or profound intellectual disabilities – children who were not accommodated in special schools. In these day-care centres each care team consisted of a trained individual who provided learning support to children with special needs, a speech therapist, a physiotherapist, an occupational therapist and an educational psychologist. Both these centres received funding from the Departments of Health and Social Development.

Non-probability purposive sampling was utilised in this study. In order to qualify as a participant for this study, the families had to meet the following criteria: (1) At least one child in the household had been diagnosed with severe or profound intellectual disability; (2) The child's diagnosis had been made at least one year prior to the study; (3) The child was registered at one of the two participating centres; (4) The household included two parents; (5) The parents were fluent in either English or Afrikaans – this criterion would ascertain that the data were comparable in terms of Western cultural influences through language; and (6) The families were from the middle- to low-income group – this criterion

would help to equalise the effect of income as one of the most potent variables in family functioning (Wilkinson & Pickett, 2009).

Families who met the inclusion criteria were identified with the help of the two managers of the respective day-care centres, who sent me (first author) a list of possible participants and their contact details. There were 16 families who met the criteria. Telephonic contact was initiated with the families to briefly explain the purpose of the study and what would be expected of them if they chose to participate. Once the families agreed to take part in the study, a fixed appointment was scheduled at a time that suited me (first author) and the participants. With the exception of one interview that was conducted in a quiet restaurant (at the request of the parents), all other interviews took place at their residences.

Data saturation occurred after 11 interviews. Both parents were present during all of the interviews (one interview per family). The demographic profile is outlined below.

- The 11 participating families were all Afrikaans speaking and Christian. Regarding the socio-economic status of the families, three families fell into the middle socio-economic class, according to the household income report of Masemola, Van Aardt, and Coetzee (2012), and the remaining eight families fell into the low emerging and emerging middle class. The age of the mothers ranged from 24 to 56 years, with an average age of 41.7 years. The age of the fathers ranged from 29 to 55 years, with an average age of 43.8 years. Ten of the couples interviewed were married, and the other couple was engaged and had lived together for four years. The duration of the marriages, including the relationship of the couple who lived together, ranged from one to 33 years, with an average duration of 17 years.
- Of the 11 children with severe or profound intellectual disability, seven were male and four were female. The ages of the boys ranged from 3 to 23 years, with an average age of 14.1 years. The girls' ages ranged from 4 to 24 years, with an average age of 14.3 years. The period since the diagnosis of the children ranged from 2 to 24 years, with an average time interval of 13.5 years. The causes of the children's intellectual disabilities were brain damage (hydrocephaly) – two children; brain damage (developmental defect) – five children; brain damage (accident) – one child; medical condition (meningitis) – one child; medical condition (at birth) – one child; and genetic condition – one child. All the children primarily had severe or profound intellectual disability along with additional disabilities, like sensory disabilities (visual, speech and hearing impairments), cerebral palsy and epilepsy. Some children had more than one additional disability. There were seven children with secondary cerebral palsy, nine children with secondary speech problems, two were epilepsy sufferers and one child had a secondary visual impairment.

## **DATA COLLECTION**

The interview schedule consisted of two parts. First, the participants provided the following information in a biographical questionnaire: age, gender, race, home language, family composition, number of children in the family, age of children, information regarding the child with the disability, the household's monthly income and the parents' employment status. Secondly, a semi-structured interview was conducted with all the participants during which the main open-ended question, as well as a number of probing questions, were asked: What characteristics, strengths and resources helped your family to adapt after the diagnosis of your child's intellectual disability? Semi-structured interviews are the most common interview type and are often used in qualitative research. This enabled the researchers to explore the participants' experiences and views in depth (DiCicco-Bloom & Crabtree, 2006).

### **Data-collection procedure**

During the interview the purpose of the study was explained to the participants to ensure their understanding of what the research entailed. Ethical considerations were then explained to the participants, and they were assured that all information would be kept confidential and that their

participation would be anonymous. Voluntarily participation was also emphasised. All the families who took part in the study signed a consent form. However, it was made clear that they could still withdraw from the research at any time, without any negative repercussions. Once the forms were signed, the participants completed the biographical questionnaire, after which I (first author) asked their permission to record the interview electronically. All the participants agreed to this. As soon as the participants were put at ease, the interviews commenced with asking the open-ended question. Through further probing questions the participants were encouraged to expand on specific issues. The interviews lasted between 40 minutes and two hours. I (first author) transcribed the electronic recordings to protect the participants' identities.

## DATA ANALYSIS AND TRUSTWORTHINESS

The transcribed interviews were analysed using Braun and Clarke's (2006) technique of thematic analysis. During data analysis we realised that additional information was needed to expand on specific themes that emerged. Three participating couples were identified and contacted for a follow-up interview. This interview focused on specific themes, viz. perseverance, mutual love between family members, humour, planning and spiritual support. The participants were asked to elaborate on certain aspects of these themes that had emerged in their previous interviews.

To ensure the credibility of this study, the results of the study were compared with previous research; the study methods were fully described to ensure that other researchers could replicate the study; I tried my best to remain objective at all times and avoided condemning the participants' views; I also discussed the findings with other academics in the field of family psychology to gain alternative opinions relating to the topic at hand and thereby to strengthen the credibility of the study (Lincoln & Guba, 1985).

Lincoln and Guba (1985) describe four constructs that determine the trustworthiness of a qualitative study. These constructs are *credibility*, *transferability*, *dependability* and *confirmability*. To establish *credibility*, I (first author) made use of probing during the interviews to elicit more detailed answers from the couples. Credibility was further enhanced through (i) frequent debriefing sessions with the second author (research supervisor); (ii) establishing the validation of findings by comparing this study's findings with prior research findings; and (iii) providing in-depth descriptions of the relevant constructs and of the participants in this study. *Transferability* was achieved by an in-depth description of the data-collection procedure, which ensures that future researchers fully understand the context of this study. Furthermore, by describing the demographic characteristics of this study's participants, other researchers are better enabled to transfer these findings to other population groups in which they are interested. *Dependability* was enhanced through a detailed description of the research design, data-collection procedure, and analysis method employed in this study, which ensures that similar research could be replicated in the future. *Confirmability* was achieved through constant self-reflection by both researchers, in which we scrutinised our own predispositions. Furthermore, confirmability was also pursued through peer debriefing. Transcripts were given to another researcher who was familiar with thematic analysis, but was not involved in any aspect of this study. Her opinions on the emerging themes were discussed, compared and integrated into the themes identified by us (both authors).

## FINDINGS

On the completion of the thematic analysis, four themes and 17 subthemes had emerged. These themes were spiritual resources, positive family characteristics, social support and family organisational patterns. These themes and subthemes represented the resources and characteristics that helped the participating families to adapt to their circumstances and to continue living their lives after facing their child's diagnosis.

## **Theme 1: Spiritual resources**

The first theme that emerged, namely spiritual resources, was mentioned by all the parents, who felt that spiritual resources helped their families adapt. These resources (subthemes) included: faith in God, reformulation of the crisis, prayer and spiritual support.

### ***Subtheme 1.1 Faith in God***

All the participants in this study identified their faith in God as the main resilience resource that helped their family through the adjustment process. Their faith in God shaped the foundation of their lives, and it was deemed important to base their lives on a strong faith. Eddie's mother put it this way:

*First, we have to place God there, as our pillar of strength, as our mediator. And that is what our foundation is built on: on God. Because we can't, our foundation can't, if our foundation is not built on God, uhm, then this situation just won't work. ... You know, if you know God, and God is part of your life, then nothing is too heavy.*

Some participants also argued that one's life would turn out right and good, if one lived according to God's will and established yourself in Him. Mia's father also deemed it important to trust God:

*Yes, look, the foundation of our lives is basically our faith and our grace from our Creator. I mean, there is absolutely ... without Him we couldn't make it at all. But, I think He, the Father, knows what He is doing and He gives you the ability to handle it too.*

The supporting strength from having faith in God is also reflected in the studies of De Klerk and Greeff (2011) and Small (2010), who found that the parents of a child with a disability find comfort in the conviction that God will help them during a crisis, and that their faith helped them through achieving better adjustment in their family.

### ***Subtheme 1.2 Reformulation of a crisis***

Some participating families used their religious beliefs to reframe their situation into something more positive. The religious beliefs evident in these families to reformulate their situation included the experience of God's grace and a firm belief that God had a plan for their family.

Some parents reformulated the crisis by saying that, even though their child was extremely disabled and doctors had little hope for their child, God was so good to them and His grace was so great that it helped the family to reformulate their crisis, thus making their lives more positive. Ettienne's mother put it this way: *"If the grace from above was so good to Ettienne, why should I doubt? The grace from above, I have to say, carried me through."* These families thus found a more positive outlook on their situation by reformulating the situation by focusing on God's grace.

Other families reformulated their situation into something more positive by focusing on God's plan in their child's life. The fact that the parents believed that God had a plan for their child led these families to view their situation in a more positive light. Hennie's mother explained it as follows:

*My child often got lost and every time they found the child in church. And that day it made me realise again, the Lord has a special purpose for my child's life, because every time he gets lost, we find my child in the house of the Lord. Not in another place.*

The participants in this study accepted their situation and reformulated their circumstances by focusing on God's grace and His plan. Accepting their situation helped the families to find positive meaning in it, which had a positive outcome for them. Accepting their circumstances helped parents to reformulate an adverse situation into a more positive experience (Greeff & Nolting, 2013; Hartshorne, 2002).

### ***Subtheme 1.3 Prayer as a spiritual resource***

Several participants reported that prayer helped their families adapt to this continuous familial crisis. According to these participants, there was much power in prayer and it was difficult to cope without prayer, since it brought tranquillity and new hope during a crisis situation. When they no longer knew

what to do, they could pray and ask God for guidance. In this way, prayer offered something dependable to hold onto. Ettienne's mother stated it this way:

*And pray, pray. We believe in prayer, to ask God. Sometimes it's just, you just don't feel it anymore. You feel, yoh. It sometimes seems like I just want to lie down and so, but when I finish praying then I feel like another person again. ... Just, He lifts you up.*

Based on the formulations of participants on the meaning and value of prayer in their lives, it is clear that prayer was an important spiritual resource that gave them something to hold onto (Small, 2010; Walsh, 2012).

### **Subtheme 1.4 Spiritual support**

Some of the participants reflected on the spiritual support they received from their church and spiritual leaders. This support was expressed by churchgoers who prayed for the child with the disability, and by spiritual leaders – for example, congregation members, people on the church council and pastors – who supported the family emotionally and stood by them in times of need. For example, Zani's mother said, "I went to church, the pastor prayed for her and then two days later she was healthy. Not completely healthy, but she started showing signs of improvement". Nico's mother referred to spiritual support by saying, "Everybody in church supports me a lot and prays for us, and that's very important."

It was imperative for these participating families to draw on spiritual support within their immediate environment. This meant being amongst other people, opening themselves to assistance and then accepting help. The support enabled the families to continue with their day-to-day tasks and responsibilities, and helped them to continue living their lives (Ahlert & Greeff, 2012).

## **Theme 2: Positive family traits**

In the second theme various features were identified by the parents that helped their family through the adjustment process. These traits were invaluable and played an important role in keeping the family together and confirming to the child with the disability that he/she was just as important as the other siblings.

### **Subtheme 2.1 Perseverance of the parents**

Some (five) parents said their perseverance as parents helped the families with the adjustment process. According to these parents, it was important to stay strong, emotionally controlled and have a positive outlook in spite of difficult circumstances. These participants described perseverance as the inner strength that individuals obtain through various sources (such as faith, prayer, support from others and physical activities); and that helped them to develop resilience and optimistically plan for the future. Zani's mother expressed this as follows:

*Perseverance is definitely one of the most important characteristics you could have as a parent, because without it, it means that you will stop pushing and just give up. Everyone who has a special child will at one point reach a situation where you will have to have persevere, and if you don't push through it, then it is the child who is going to suffer. For example, when my daughter was hospitalised with bacterial meningitis, we were told she was not going to make it. We refused to accept it ... and we won the battle.*

All parents who referred to perseverance emphasised that one should always remain strong, confront obstacles, find solutions and remain persistent (Field & Hoffman, 1999; Walsh, 2012).

### **Subtheme 2.2 Mutual family love**

Love was identified as an important source of family resilience by most couples. These participants referred to love in various ways. Primarily, it was the love for their children, and they argued that it was vital to shower the child with love to form a close bond with the child. Zani's mother stated:

*And another thing that also helps, is love. You have to show your child an incredible amount of love. The love I'm talking about is, you need to give your child hugs and kisses often.*

*Children with special needs thrive on positive attention and love. If your child is sitting and playing on the mat, don't just walk past and say, "you're playing nicely". Walk to the child, bend down and rather say, "you're playing very well, Mommy is proud of you". Then give 'em a kiss on the head and say "I love you.*

A different form of love identified was the love within a family unit – to love one another as a family – because it shows the other family members that you are supportive of them and you care for them. Lisa's father explained this kind of love as follows: "As a family you obviously love one another, and if this was not so, then you cannot care about someone else."

Other parents mentioned God's love and that one must have His love in your life to better adapt to difficult circumstances. Eddie's mother expressed her views on this as follows:

*... and love. Today in service, we once again heard about love, care. If this is part of your life and you have God's love and you reach out, then nothing is too heavy for you.*

Mutual love and demonstrated love between family members could thus play a crucial role in the adjustment process of families (Greeff & Van der Walt, 2010; Powers, 2000).

### ***Subtheme 2.3 Patience***

A few (three) parents indicated that patience played an important role in their family's adaptation to the demands faced by the family. Participants confirmed the challenges of having a child with an intellectual disability. It required energy and stamina, especially if the child was unable to do anything for him/herself. Parents often have to fight their emotions, especially if the child has additional behavioural problems. For example, if the child cannot speak, the parent has to deduce what the child wants, based on how the child is crying. This is exhausting and requires much patience and perseverance. Many mothers admitted that they struggled with patience themselves, but were grateful for their husband's calm nature and patience. Jannie's mother described her husband and daughter's patience as follows:

*My husband's nature. If he didn't have that peaceful nature (laughs), men don't typically have a peaceful nature like that. And luckily my daughter as well. I have this wonderful daughter who always understands and who is always calm and never complains.*

Zani's mother emphasised the importance of patience and how one's patience is tested:

*The thing that worked best was patience, because without patience you can't do anything. It almost feels like you want to kill the child if you don't have patience.*

It is important to accept a child just as he/she is and to encourage the child to shape his/her own personal identity, but this demands a great deal of patience from the parents (McCubbin & McCubbin, 1996; Small, 2010).

### ***Subtheme 2.4 Humour***

Two parents highlighted the importance of humour as a source of family resilience. According to these participants, humour can come from two sides, namely the child with the disability, as well as from other family members. Humour helped them most during difficult moments, because it helped to bring a joke into the situation, to laugh again, and thus to de-escalate the sombre mood. Bertie's father expressed the value of humour as follows:

*And one last thing for me is humour. At times, you reach a stage when you can either become discouraged, or get angry, or laugh. And you know what, laugh about it, because the other stuff won't help you.*

Walsh (2012) is also of the opinion that using humour and laughing despite experiencing problems are important aspects of resilience.



### **Theme 3: Social support**

The third theme was identified by all the parents as an important source of family resilience. Social support in this context refers to support from within the family unit, the extended family network, friends and the community, and online. Social resources can be divided into practical and emotional support. Emotional support refers to the availability of someone with whom family members could discuss problems, share feelings and talk about concerns. Practical support refers to healthcare workers who provide family members with advice and guidance, offer information on available community resources, and devote their time and skills to the family (Hastings, Allen, McDermott, & Still, 2002; Walsh, 2012).

#### ***Subtheme 3.1 Support from within the family unit***

This form of social support was deemed important by all the participating families. Some parents mentioned family members who played a valuable role in the family's adaptation process. Collaboration within the family unit was emphasised by several participants, and the parents indicated that they also supported each other as spouses. The value and importance of support from other family members (in this case from the spouse) was expressed by Zani's mother:

*We work well together. I work with her during the day and when my husband comes home, I move away from her and he takes over. He puts her to bed in the evening, that's his job. He must give her food, and during the day it is my job.*

Family members facilitate the family's adaptation processes – especially in families with additional children. The extra hands to help care for the disabled child aid the parents, who thus do not have to do everything themselves (Greeff & Van der Walt, 2010; McCubbin, Thompson, & McCubbin, 2001; Small, 2010; Walsh, 2012).

#### ***Subtheme 3.2 Support from the extended family network***

All participating parents said that support from the extended family played an important role during the family's adjustment process. Participants referred to various types of practical support regarding tasks (such as babysitting, helping with exercises, or helping with other housework). This assistance meant a lot to the parents, because it gave them a break to have time for themselves. Jannie's mother described the support from her mother and her sister as follows:

*We often felt that way, if it wasn't for my mom who took him in during the first days, then I think we would've really thrown in the towel. And grandma said she woke up every hour during the night to turn him, so he didn't get bedsores. And I have a sister who is in nursing. Luckily, she helped us a lot. ... And it was pretty good for our marriage too and we could also spend some time with our, I almost want to say, "remaining child."*

Extended family played an important role in the adaptation process (De Klerk & Greeff, 2011; Small, 2010). In the families participating in this study, the grandparents were the main sources of support.

#### ***Subtheme 3.3 Support from friends***

Most (eight) couples pointed out that friends were an important source of social support. However, some (five) couples also indicated that they had also experienced negativity from friends and that they had lost many of their friends over the years. Many participants believed that this happened because their friends could not understand and accept the child's disability. Others blamed it on "ignorance". The support of friends did, however, evoke a positive response from most participants. A distinction can be made between practical and emotional support. Mia's mother referred to the emotional support she received from friends:

*I talk about it with my friends. So, it's nice for me. They are also very involved with us and it's nice, just to talk to them and say, "yoh, it's quite hard."*

Zani's father referred to the practical support they received from friends:

*Our friends understand that she is special. They never turned their backs on us, but rather supported us. If my wife or I could no longer go on, they took Zani with them just for a little while, just so we could recharge.*

Support from friends can therefore be an important source of social support – especially if it is friends one can lean on in times of need, with whom one can talk and ask for advice about anything, and who can help and assist in caring for one’s child (Taanila, Järvelin, & Kokkonen, 1999).

### ***Subtheme 3.4 Community support***

All the families identified the community as an important source of social support for the family. This included support from the day-care centre; from health-care workers such as doctors, occupational therapists, physiotherapists, psychologists, social workers, and speech therapists; from schools; from the parents’ employers; and from others in the community. While these support resources were considered important, there were some parents who mentioned negative experiences with community members. Despite these negative experiences, community support played an important role in the adaption process of the participating families in this study. Community support can be divided into emotional and practical support. For example, Lea’s mother described the emotional support that their family received from the community as follows:

*... and every time we came to the clinic, they always supported us with words, talking to us about how to care for the child now and what we should do.*

An example of practical support from the community was given by Danie’s mother:

*Then I come home, then there are bowls of food in front of my door, food people just brought. They probably assumed that we didn’t have time, because he was crying so much, one was always busy with him. His school supports us incredibly. If we want to go somewhere, they’re always ready to send someone to babysit him, that we can go out. So, it also helps a lot.*

The diverse nature and importance of support from the community are also reported by Catherall and Iphofen (2006). Although families do not necessarily have access to the same sources of community support, it is important for them to be on the outlook for possible sources and then also to use them. This is illustrated in the following two comments by participating families.

One parent mentioned the impact of the internet on their family’s adaptation process. Ever since their child was diagnosed with an intellectual disability, they used the internet to read up on her condition, to get tips on what to do, and to find supporting aids (such as programmes that helped children to read, exercise and reach basic milestones). Zani’s mother highlighted the importance of online support as follows:

*And what helped most was the internet. There are a lot of resources available, to find out about illnesses and everything. For example, if your child is struggling with potty training because she is disabled, there are websites that explain to you, step by step, how to potty train your child. ... So now you're sitting at home, what are you doing with your child? Your child must learn. The first thing you do is go to Google. You see what’s on Google. ... On Google, there are programmes, exercise programmes, because if you can’t afford an occupational therapist, who else will explain to you, step by step, what exercises should be done for which muscles in the body.*

Furthermore, two couples said it was important to seek support and to accept the support of others. These participants admitted that they sometimes felt like failures when asking for help, but they had come to realise that no one can do everything themselves and that you need to acknowledge that you need the help of others. Danie’s mother expressed the search for support as follows:

*And don’t be afraid to ask, you know, and if people offer, take their offer to heart and use it.*

It is evident that social support can have an impact on families only if the family is receptive to it and can use it to the benefit of the family.

#### **THEME 4: FAMILY ORGANISATIONAL PATTERNS**

In the fourth theme several participating parents indicated that their families used certain organisational patterns to adapt to their situation. Three organisational patterns (subthemes) emerged in this study. These were family routines, flexibility in the family's daily functioning, and planning.

##### ***Subtheme 4.1 Family routines***

For five of the participating families, routines at home, and more specifically the routines of the child with the disability, played an important role in the adaptation process. Some participants indicated that it was important to keep the child in his/her routine in order to establish stability and avoid confusion for the child. Zani's mother believed it important to have fixed routines for the child because, without routine, the child could develop behavioural problems:

*Don't break that child's routine. If you break it, you will have problems and it's like tantrums – she keeps screaming. So, you have to do the same thing every day, weekends, holidays,*

Ettienne's mother, on the other hand, mentioned how the child's health could be affected if he did not follow a fixed routine:

*He followed a good routine from a very early age, and it stayed with him to this day. And if one deviates from the routine, he gets epileptic attacks.*

According to McCubbin and McCubbin (1996), routines in family life are an important characteristic of resilience. Family routines make the family's life more predictable and handleable, and help family members to share tasks that are related to taking care of the child with the disability. This helps the family to adjust (Catherall & Iphofen, 2006).

##### ***Subtheme 4.2 Flexibility in the family's daily functioning***

Even though routines bring stability to the family unit, it is important that the family is adaptable if they have a CSPID. Some participants mentioned the adjustments they made as a family in their daily life, as well as physical alterations they made in their homes. Bertie's father mentioned adjustments related to tasks that had to be done:

*... certain things that he can do, he does himself. Uhm, what he can't do, we help him with, because we are his parents. Uhm, and as I said, to cope with the disability itself is pretty easy, you just have to adjust, you do what the child or the person can't do, help him or her with that.*

Participants reported that they had to make changes to their homes so as to make it easier for the child with the disability to move around. Mia's mother had the following to say on this:

*Mia probably last bathed two years ago, because my back can no longer handle bathing her, so we built a bench in the shower and adjusted the shower in this manner.*

McCubbin and McCubbin (1996) refer to adaptations that a family has to make in its established pattern of functioning (including changes in family roles, patterns of functioning, rules and lifestyle) to help in the adjustment process. Similarly, Greeff and Van der Walt (2010) found that families who are prepared to actively learn and experience new things adapt better and more easily to their circumstances. Walsh (2012) adds that the adaptability of family members plays an important role in the adjustment process of the family.

##### ***Subtheme 4.3 Planning***

For six of the participating families, planning played an important role in the adaptation process when facing difficult circumstances. Participants mentioned that everything always had to be planned well in advance if they were to go anywhere. For example, if the child was in a wheelchair, they first had to

make sure that their planned destination was wheelchair-friendly and could meet their child's needs. For these families it was vital that everything regarding the child was planned and thought through. Impulsivity was avoided. Some participants also reported that not just anyone could babysit their child if they wanted to go out alone as a couple. It was deemed important that the right person, who would understand the child and with whom the child would be comfortable, looked after him/her. Danie's father described planning in the following example:

*We can't just decide we're going away for a weekend. It doesn't work like that. You have to plan your things around him. One has to sit with him all the time, entertain him, keep him happy.*

Another form of planning highlighted by participants related to the child's future. According to one couple, it was important for them to focus on their child's future early. They had to be prepared for when they as parents could no longer be there and when no other options regarding care for their child would be available. It is also important to find the right school or day-care centre for the child. Zani's mother explained this form of planning as follows:

*Planning for the future is very important to me, because you have to think ahead about what is best for your child's future. In Zani's case, it is a school for her. I can't just pick any school; you have to look at your child's needs and all those kinds of stuff. And there must always be a plan B and sometimes a plan C as well.*

For these participants, it was imperative to plan their lives around their child to ensure that their child would be happy and always get the best care. The importance of planning as a source of resilience is also reflected in Walsh (2012), who holds that a proactive attitude (preparedness, planning and prevention) is important when future challenges are tackled.

## DISCUSSION

Based on the findings of the current study, answers to the question, "Which characteristics and resources help families adapt after their child has been diagnosed with a severe or profound intellectual disability", can be summarised with reference to the following themes: spiritual resources, positive family traits, social support and family organisational patterns.

Regarding spiritual resources, this study found that faith in God, a belief that God has grace and a plan with their child's life, prayer and spiritual support helped families through difficult times. Walsh (2009) also refers to spiritual resources, such as strong faith, prayer, meditation, and involvement with church and other spiritual organisations as characteristics of resilience. Since all the participants in this study identified as Christians, it is understandable why a strong faith in God emerged as a major spiritual resource for their families' adaptation. This finding is in line with the findings of De Klerk and Greeff (2011). Some parents used their religious beliefs to reformulate their situation into something more positive. This helped parents to find meaning in their circumstances, to accept them and to adapt to their situation (Walsh, 2012).

In this study four positive family traits were identified as family resilience factors, viz. the perseverance of the parents, mutual love among family members, patience and humour. If a family's potential and strengths are emphasised during a difficult time, it can help that family to move away from self-blame, helplessness and a sense of failure, while establishing a feeling of pride, self-confidence and a "can-do" attitude in family members (Walsh, 2009, 2012).

In the current study different types of mutual love among family members were identified. The first type was love for their children. Another form of love was love between family members. If this love is demonstrated, it shows other family members someone is there for them and cares about them. Through this, parents demonstrate to children how to love. Several mothers mentioned that their husbands were very patient, and how life for their families would have been much harder if this was not the case. According to Powers (2000), it is important that parents show love to the child from birth by accepting the child just as he/she is.

Social support was identified as a third source of family resilience in the current study. This included support from within the family, support from the extended family network, and support from friends and the community. Several studies have reiterated that social support is an important resilience factor in the adaptation process (Catherall & Iphofen, 2006; Greeff & Van der Walt, 2010; Walsh, 2012). The informal support of family and friends, as well as formal support from the community, schools and doctors, helped parents get information and emotional and physical support, which in turn reinforced their perseverance and strengthened the minds of all family members.

The fourth family resilience theme identified was family organisational patterns, which was also identified in several earlier studies (Catherall & Iphofen, 2006; McCubbin & McCubbin, 1996). Organisational patterns included family routines, flexibility in a family's day-to-day functionality, and planning. Family routines make the life of the family more predictable, while contributing to stability in the life of the child with the disability. The ability to constantly adapt to change (including changes in family roles, functioning patterns, rules and lifestyle) is also a source of resilience. When families are willing to actively learn and experience new things, they adapt better and more easily to changing circumstances (Greeff & Van der Walt, 2010). A proactive attitude (preparedness, planning and prevention) is important when addressing future challenges (Walsh, 2012). By doing so, a sense of security is created, and the family knows where they are heading. At the same time, it creates hope that the future can be even better.

## CONCLUSION

The findings of this study confirm that faith in God, social support, perseverance, mutual love, patience, humour, family routines, family flexibility in their daily functioning, and good planning are important characteristics in family resilience. These features relate to both the well-being of the child with a disability and the adaptation of the family.

The social relevance of this study is grounded in the resilience features identified, which can be used as a point of departure to develop interventions that help families with a child with a severe to profound intellectual disability to adapt to this family crisis and to continue living their lives. These results are especially relevant in the light of the fear of the prognosis faced by these parents, their worry and anxiety about the future, their feelings of shame and guilt, and the stigmatisation and social rejection they experience. This study contributes to the existing knowledge on characteristics that help families adapt to the demands of a child with an extreme intellectual disability, thus helping to reduce a gap in the literature.

## RECOMMENDATIONS FOR SOCIAL WORK PRACTICE AND EDUCATION

The findings of this study offer tips for social workers, as well as for other parents in similar situations to the participants in this study, on how to handle the child (for example, with love and a lot of patience), how to care for their child (tips on the internet, a fixed routine for the child), and what to do to improve the functioning of the family as a whole (patience, perseverance, mutual love, a search for support, fixed family routines, good planning, and strong faith). These characteristics of family resilience can be used by families or can be developed through well-considered interventions by social workers. All of these can contribute to an improvement in the child's welfare, and better adaptation by the child and other family members, and hence better general family functioning.

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